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LONG-TERM CARE INSURANCE

HEARING

BEFORE THE

COMMITTEE ON
LABOR AND HUMAN RESOURCES
UNITED STATES SENATE

ONE HUNDREDTH CONGRESS

SECOND SESSION

ON

REVIEW OF THE NEED FOR LONG-TERM CARE INSURANCE

AUGUST 3, 1988

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LONG-TERM CARE INSURANCE

WEDNESDAY, AUGUST 3, 1988

U.S. SENATE,
COMMITTEE ON LABOR AND HUMAN RESOURCES,
Washington, DC.

The committee met, pursuant to notice, at 10:40 a.m., in room SD-430, Dirksen Senate Office Building, Senator Edward M. Kennedy (chairman of the committee) presiding.

Present: Senators Kennedy, Hatch, Metzenbaum, and Simon.

Also present: Congressman Claude Pepper.

The CHAIRMAN. We thank everyone for their patience, including our colleagues here. We have had disruptions with our votes, and we are going to have a series of additional votes. We have some important witnesses. We want to afford them all the courtesy that is possible. We want to again thank our very distinguished colleague, Congressman and Senator Pepper, for joining with us.

I will include my statement as if read in the record at this time and recognize the Senator from Utah.

[Statement of Senator Kennedy follows:]

OPENING STATEMENT OF SENATOR KENNEDY

The CHAIRMAN. America has made vast strides in the past half century in providing the secure and dignified retirement that should be the birthright of every senior citizen. Social Security, Medicare, and, most recently, passage of the Medicare catastrophic legislation, have done much to liberate our senior citizens from those dark days when the blessings of long life were too often blighted by the curses of poverty, illness, and despair.

But one great gap in the retirement security safety net remains: our national failure to protect senior citizens against the devastating cost of long term care. Long term care insurance is as essential to the current generation of the elderly as Medicare was to the last generation. Every senior citizen who has ever needed nursing home care or home care knows that—and so do their spouses, their children, and their grandchildren.

The magnitude of the long term care problem is immense. Over 1 million elderly Americans live in nursing homes today—and for every senior citizen in a nursing home, two or three more are equally disabled and equally in need—struggling to survive in their own homes, in their children's homes, or in other community settings. A smaller number of disabled children and disabled adults under age 65 also need long-term care.

The number of senior citizens in nursing homes today is high—but it vastly understates the number of those who will need long term care in the years ahead. As Americans live longer, 35 to 50 percent of all senior citizens can expect to enter a nursing home at some point in their lives. According to surveys, almost half of all American families have been touched—and often touched hard—by the need for long-term care.

One of the most distressing aspects of this growing crisis is the devastating cost of decent long-term care for the vast majority of families. For the average senior citizen, a stay in a nursing home can be as financially ruinous as a stay in the hospital used to be in the dark days before Medicare.

According to a recent study by the House Select Committee on Aging, one-third of all elderly couples would be reduced to poverty if one of them had to be institutionalized for 6 months. And for senior citizens who are single and therefore more likely to be living on the edge, almost two-thirds would be impoverished in the same 6 months.

Home care is less costly than nursing home care, but even that type of care is prohibitively expensive for most of the elderly. One out of every five married couples would be impoverished by 6 months of home care; one out of three would see their hopes for a dignified retirement vanish within a year. And for senior citizens who are single, two out of three would be impoverished within a year.

Crushing as these expenses are in financial terms, they are even more destructive in human terms. Disabled senior citizens who cannot afford assistance are condemned to lives of loneliness, misery, and despair. Even if they manage to recover physically from the stroke, fractured hip, heart attack, or other disability that led to confinement in a nursing home, they often cannot go home, because the financial burden of treatment and recovery has wiped out the savings that made life at home possible, let alone comfortable.

When an infirm individual must be cared for in the home by a spouse, by a parent, or by a daughter or son with children of their own, the financial and emotional burden of providing needed care can become so great that it destroys all possibility of happiness—both for the senior citizen and for the family members who provide the care.

These conditions are unacceptable in America in 1988, and the legislation I am introducing today is designed to put an end to these human tragedies.

The Lifecare Program will provide comprehensive protection against the cost of long-term care, whether that care is provided in a nursing home or an individual's own home. It is constructed on three fundamental principles. First, it will be universal. Everyone will be able to participate. All insurance programs work best with broad participation: they are most effective in protecting both society and individuals, and they are most cost-effective, too.

Second, the program will be available to all without regard to ability to pay. Social insurance programs have wide support because rich and poor contribute alike and benefit alike. It is no accident that Social Security and Medicare are the two most broadly supported and widely loved social programs ever enacted, and their successful approach will be a cornerstone of the Lifecare Program.

Third, the program must be comprehensive enough to provide all essential services without the need for private supplementary insurance. Studies by the Brooking Institution have shown conclusively that private insurance cannot possibly reach all the elderly needing help. The reason is obvious. Private insurance that is not sold on a group basis inevitably skims off the easiest risks and least costly clients and dumps the rest on government. And where gaps in a public program need to be by private insurance, it is those who need the gaps filled the most who are typically least able to afford supplementary protection.

In addition, as experience under Medicare proves, private insurance inevitably costs more than the government charges for the same protection. Administrative costs are a rock-bottom 2 or 3 percent under Medicare, compared to as high as 40 percent under private so-called Medigap policies.

When the next Congress passes a long-term care protection program—as I believe it will--I want it to be a program that truly meets the needs of our disabled senior citizens. I do not want us have to come back two decades later—as we just did with Medicare—to correct inadequacies that should have been obvious from the beginning.

The comprehensive program that I am proposing today will come in two parts, analogous to Medicare. Part A would cover the full cost of home care and the first 6 months of nursing home care. It would be fully financed with Federal funds. Part B would cover longer stays in nursing homes. Enrollment in Part B would be voluntary, and it would be financed two-thirds by premiums from the elderly themselves and one-third from public revenues.

Senior citizens, disabled children, and disabled adults under age 65 would be eligible under Part A for home services, adult day care, and respite care if they are totally unable to perform at least one of the so-called normal activities of daily living or are significantly disabled in two or more of these activities. These activities include transferring (for example, from a bed to a wheelchair), bathing, dressing, eating, and using the bathroom. Those who need care because they are mentally disabled, by Alzheimer's disease, for example, would also be covered.

Services would be based on the degree of disability and the need for care, with limits on the daily or weekly cost, but no limit on the length of time as long as the need continued.

There would be a modest copayment to assure that services would be provided only when needed, but the copayment would be related to ability to pay, so that no one is denied needed services because the copayment is too burdensome.

The home care program would be organized and managed at the local level by long-term care coordination agencies designated by State governments, which would retain a fiduciary responsibility for their operation under Federal guidelines. This state-local delivery system follows a model of home care that many states, including Massachusetts, have already shown can deliver high quality, humane, comprehensive, and cost-effective care to disabled elderly citizens.

In addition to covering home care, Part A would also fully cover the cost of the first 6 months of a nursing home stay. Nursing home care would be provided rather than home care, if nursing home care was necessary and in the best interest of the individual.

For protection against the cost of longer nursing home stays, individuals could enroll in Part B of Lifecare. After an initial eligibility period subsequent to the bill's enactment, individuals could choose to enroll at either age 45 or age 65. Individuals enrolling at age 45 would gain the benefit of lower premiums and protection during the period between age 45 and age 65.

The Lifecare Program I have outlined today will cost an estimated $20 billion a year when fully phased in. Obviously that cost is great, but the benefits are even greater. I believe that this is one program where the American people will say "Amen" when we ask them to pay for it—and end this shameful blight on the lives of senior citizens and their families.

There are a number of possible ways to pay for Lifecare. The one I favor is to increase the current income ceiling on the payroll tax for both employees and employers. If we raise the income ceiling from its current level of $45,000 per year to $75,000, we could pay most of the cost of Lifecare. I personally believe that it would be fairer to eliminate the income cap entirely, so that all Americans, including the wealthy, pay the same share of their income to support these important programs. Taking that step would raise more than would be needed to support Lifecare, and we could use the surplus to lower the tax rate for all workers.,

A number of other possible financing sources to pay for long term care, such as inheritance taxes and higher taxes on alcohol and tobacco, have been suggested. I intend to work with the tax committees and the affected groups to find the method that is fairest and most generally acceptable. The key condition that we all know must be met is that this program must be self-financing. Deficit increases are as unacceptable as inaction, and I am confident that the American people and the Congress will find a way to pay for the kind of program that our senior citizens and their families need and deserve. If we are honest, we know that society already pays for long term care but in cruel and irrational ways. Public dollars now contribute more than $20 billion a year for nursing home care—almost half the total. But these public dollars, provided through Medicaid, are expended only after senior citizens and their families have been forced to pauperize themselves. I say, these public dollars should be used up front, to protect the elderly's standard of living when there is still something left to protect.

The billions of dollars of private funds that go into the current system would also be redirected under Lifecare. Today, they are extorted from the sick and their families as an unfair penalty for serious long term illness. When Lifecare is law, these private dollars will be spent through an effective, humane social insurance program that spreads the cost among all citizens.

In closing, let me say that enacting Lifecare will be a difficult battle—almost as difficult as the battle for Medicare more than two decades ago. We won the battle for Medicare, because the American people agreed that no decent society could deny affordable health care to its elderly. In 1988, the American people understand that adequate and affordable long-term care, whether in an individuals's own home or in a nursing home, is just as fundamental.

Senator Hatch.

OPENING STATEMENT OF SENATOR HATCH

Senator **Hatch**. Thank you, Mr. Chairman.

Congressman Pepper, happy to see you again. It is good to have you here.

Mr. **Pepper**. Thank you, Senator.

Senator **Hatch**. Last year, I received a letter from a Mrs. Thomas from Utah. She wrote to me and said, "I want home care, and I don't want to be alone in life."

Last month, I chaired a hearing in Salt Lake City on women and health care issues, and we heard from Mrs. Mary Ann Lewis. She testified on the day she was released from the hospital following surgery to replace a knee joint. On that same day, her husband, Bert Lewis, was also being released. Bert is a victim of Alzheimer's disease, and Mrs. Lewis cares for him in her home.

Mrs. Lewis talked about the importance of home care, because she wants her husband to live out the remainder of his days with peace and dignity.

She concluded her testimony with this request, "I plead with you to do something to expand the home health care services that are available to people like us so we can just have this one, simple wish."

I do not want Mrs. Thomas to be alone, and I want to grant Mrs. Lewis her wish. Since 1978, Mrs. Thomas, Mrs. Lewis and other Utahans have joined me in advocating increased home health care services. We have made progress, but I am going to continue the fight for my constituents in Utah who will not be happy anywhere but in their own homes.

Today there are many other senior citizens and Americans who are facing emotional and financial stress because of their long-term care needs. Currently, approximately 1.3 million elderly persons are living in nursing homes. For every one of those individuals, there are at least two living in the community receiving various kinds of care. Many of these citizens need our help to find care, pay for care, or support those who provide care.

When I began addressing this issue in 1978, there was a sense of urgency that solutions must be formulated soon. Today, that level of urgency has only increased. Congress must shoulder the issue of long-term care in a responsible fashion by supporting fiscally responsible and effective programs.

The solutions, however, will not rest entirely with the public sector. It is going to require private sector participation as well. Our jobs in Congress must be to constantly evaluate and reevaluate programs in order to find the best approaches possible. I believe the work we have done thus far gives us a good framework, and I would like to see us build on it to create a sound and effective policy that offers our senior Americans affordable and quality long-term care with a special emphasis on home health care.

Home health care benefits Americans both financially and emotionally. Let me again demonstrate some cost savings of home health care—I will refer to this home health care savings chart.

Home health care savings from cerebral palsy seizure cost is $4,867. That is a savings of $8,425 over hospitalization. A child born with breathing and feeding problems, costs $20,209, with a savings of $60,970. So cost savings are very important to home health care, and I think it can be a cost savings program.

Now, through programs like the Home Health Care Grant Act, enacted as part of the Older Americans Act, we will be able to document other benefits of managed home health care. That new authority will provide funds for three to five States to assist individuals who could avoid costly institutionalization if home health care services could be made available to them. The program will allow many more people to remain in their homes and will aid family members who provide care to their loved ones. I intend to continue working on solutions to the problem of providing adequate, affordable, long-term care services, but it is not just the responsibility of Congress or the Federal Government to help those who want to remain at home.

The private sector, citizens' groups, health care professionals and others must all contribute to developing programs at the community level.

I look forward to the testimony today, especially that of our friend, Congressman Claude Pepper, who has a keen understanding of the health care needs of Americans. He has worked very hard through the years, and working together, I believe that we can successfully grant Mrs. Lewis her wish and ensure that Mrs. Thomas will not be forced to live alone.

These are important issues. I don't think anybody has all the answers to them. I want to express my appreciation to the distinguished chairman of this committee for his willingness to innovate in this area, to hold these hearings and, of course, to help us find out just what we should do, what we can afford to do and what really is needed in these particular areas. I welcome everybody here today, especially you, Congressman Pepper.

The CHAIRMAN. Thank you very much, Senator Hatch.

Senator Metzenbaum.

OPENING STATEMENT OF SENATOR METZENBAUM

Senator METZENBAUM. Mr. Chairman, I want to commend you for introducing legislation to address the critical need for long-term health care and for holding this hearing on a "Lifecare Plan".

Just recently, Congress overwhelmingly passed and the President signed an acute health care bill which was called catastrophic health care insurance. But this legislation, though sorely needed, did not fully address the real catastrophe of inadequate long-term health care.

Whether it is Parkinson's disease or Alzheimer's disease or any other chronic debilitating illness, families bear an enormous burden physically, emotionally, and financially in caring for their family members. The national cost for Alzheimer's disease alone is over $40 billion annually.

Working couples who must care for children and for their ailing parents face unbearable pressures. I know from hearings I have held on Alzheimer's disease that families do not desert their ill parents; they want to care for them, and they do. But they must have help. The burden is too great to bear alone.

Admittedly, addressing this problem carries with it a high price. However, the price of failure is simply more than our society can afford. The problem can no longer be ignored. A nation must care for the health of its citizens; all our citizens, old and young, must have access to good health care.

The Federal Government must take the lead in establishing an equitable, long-term health care policy.

I welcome legislation such as the Lifecare Plan initiated by my distinguished colleague Senator Kennedy. No one has done more to bring national attention to this issue of health care than Senator Kennedy in the Senate and the Honorable Claude Pepper of Florida in the House.

Senator Pepper has been and continues to be a most effective champion for all our senior citizens. He has eloquently asserted older Americans' rights to equal employment opportunity and to freedom from discrimination. He is a strong advocate and a convincing and powerful witness for adequate, affordable health care coverage. I have every confidence that his heroic efforts in this area of long-term care and those of the distinguished Chairman of this Committee will be successful soon, and I hope to work with them.

The time is now for us as a nation to confront and resolve this problem.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you very much, Senator Metzenbaum and Senator Hatch, for your kind comments.

We are honored to introduce the senior statesman of the elderly, Claude Pepper. He has done more than any individual in the Congress of the United States to advance the issue of long-term care for the elderly and put it on the national agenda. His home care bill was the basis for the Lifecare legislation which I am introducing. He has long been an insightful and eloquent commentator on the needs and the hopes and aspirations of our seniors, and we welcome him here to our committee this morning.

STATEMENT OF HON. CLAUDE PEPPER, A MEMBER OF CONGRESS FROM THE STATE OF FLORIDA

Mr. PEPPER. Senator Kennedy and members of the committee, I am very grateful to you for the privilege of appearing here today in support of your very progressive legislation for the people of our country.

I agree with what President Kennedy said in 1962, that the affording of needed health care to the American people is a prerequisite to the enjoyment of the constitutional right of the pursuit of happiness. And I want to commend you for the continued leadership you have exhibited to our country and to our Congress in the health field and the progress that your bill, now before the Senate, presents.

I am very much pleased that you have made the basis of your bill the basis of the Pepper-Roybal bill to provide long-term care, and that you have included, as our bill does, men, women and children who are chronically ill. Nobody is more dedicated to the service of the elderly than you and I are, and your colleagues here today. But on the other hand, there are many people below the age of 65 not covered by Medicare, way down to the children themselves—millions of Americans who are chronically ill and who desperately need home care.

So I regard now the situation as the proper next step is for us first to consolidate the program of home care and then, as you have done in your bill, move on progressively from there.

Since 1965, when we passed the Medicare bill, we have had limited hospitalization for the elderly—60 days. By the catastrophic bill that we all supported recently, now we have moved that up to the hospitalization needed by any elderly person. And we hope that there will be in the future years further hospitalization opportunity available to the remainder of the American people.

But right now, I think we all agree the most critically demanding requirement that we have is to provide long-term care for the cronically ill and disabled men, women, and children of America. One million people of our citizenry become destitute every year, trying to pay the cost of catastrophic illness, and only this week, with Representative Joe Kennedy, I held a hearing in Boston, and here were two typical cases to exhibit that need.

Mrs. Cheryl Sanborn has spent all her savings and will soon have to sell her possessions to pay for the care of her 4-year-old son, Gregory, who is partially paralyzed and requires round-the-clock care. On September 6, her insurance for Gregory runs out, depriving them even of that small financial support. In addition, Ms. Sanborn's grandmother, a victim of Alzheimer's disease, is in need of home care, and she has a 9-year-old daughter who suffers from leukemia, although thankfully it is now in remission.

In the second case, Mr. Timothy Godfrey has spent the last 3 years caring for his mother, who has Alzheimer's disease. And I don't need to inform my colleagues here that 2 out of 3 of the elderly people of this country are vulnerable to Alzheimer's disease, and there are 3 million Americans who have Alzheimer's disease. We know that it starts off with partial paralysis and disability and becomes finally an acute disability of total character.

As his mother's condition deteriorated, Mr. Godfrey gave up his job and moved in with her to attend to her needs. For the past 3 years, Mr. Godfrey provided the bulk of his mother's care himself, often staying up days at a time. Despite these efforts, they exhausted her lifetime savings of over $25,000 and his savings of $10,000. Sadly, last year, he was forced to put his mother on Medicaid, which in turn put her in a nursing home.

I remember my own dear mother said to me in the last years of her life, "Son, don't ever let them put me in a nursing home."

Elderly people, people generally, don't want to be taken out of their homes and their accustomed environment which is so sentimentally meaningful to them and put in a nursing home. So the Pepper bill, H.R. 3436, gives them the opportunity in most cases to get the care that will sustain them in the home.

Now, you have, Senator, have gone beyond our Pepper-Roybal bill, and I commend you for it, and added in 6 months of nursing home care, which is very essential in the care of these individuals of whom we seek to aid. That is provided under your bill by social insurance, for which I commend you.

Then, you have provided Federal insurance beyond that, so that the nursing home care may be permanent or long-term in the duration for that individual.

But we start off in your bill, as we do in ours, with the basic needs of most people of our population—home care. Home care is the cheapest and the most generally desirable for people who can be kept out of the nursing home. And then you recognize that there are those who need to go beyond the home care stage and get some care in the nursing home.

I have taken the position, as I did before the Ways and Means Committee in the House yesterday, that I think we should start with basic home care legislation for all men, women, and children who are chronically ill and then perfect that bill in any way we can, and then add onto it whatever we feel we can properly afford. We didn't take that step in the Pepper/Roybal bill because the estimated cost of that bill by the CBO is $27 billion over the next 5 years. The tax that we would levy in our bill is a 1.45 percent charge on income over $45,000 a year. And that would yield, the Congressional Budget Office indicates, about $34 billion over the next 5 years; so that we estimate a few billion over the estimated cost. Now, that could be applied to nursing home care or to other services that might be added to those that would be provided in the bill.

All of us are anxious to see to it that at least basic home care is available to the critically ill people of this country. Out there, there are those desperate people, struggling to save their homes, struggling to protect the meager savings that they have, and this will help them to do so.

The average income of the American family is about $27,000, and the average savings of the American family about $10,000. So we see how limited those resources are in meeting the needs of catastrophic or long-term illness.

So Senator, I hope we can work together to achieve these high aims that we cherish. They are crying out there, millions of people, for this kind of legislation. I will give only one example.

In Fort Lauderdale, which is near my home in Miami, my niece called me the other day and said a lady in her community called her on the phone. She said,

> My father and I live in our home. I have to work to support the family. I have been able to take care of my father, who has Alzheimer's disease, by being home at lunch in the daytime and being home at night. Now his disability has progressed to the point where that is no longer adequate for his care—he will fall out of the chair, fall in the bathtub, fall on the stairs, or the like. If I quit work, there is no support for the family. I don't have the money to hire somebody to look after him when I'm not there. I don't have the money to put him in a nursing home.
>
> Call your uncle and ask him when he thinks maybe his bill, and the bill that he and Senator Kennedy and them are working on up there, may take effect.

So there are millions of people waiting hungrily, as it were, out there for legislation that we are advocating here and that we are trying to progress.

So I am proud to join you, Senator Kennedy, in making some progress toward trying to ameliorate the despair, give a little more hope, a little longer and happier life to so many of our fellow citizens.

Thank you very much.

The Chairman. Thank you very much, Congressman Pepper, for a very eloquent statement and for an insightful one in terms of this challenge.

Let me ask you how you respond to those who say can we afford either the Pepper bill or the Lifecare bill which I have proposed; can we afford it in our society, given the size of the deficits that we have? How do you answer that?

Mr. Pepper. Senator, I am glad to cite the poll that Lou Harris presented in the House to my committee. He conducted a poll on this very subject, the Pepper-Roybal bill. And he found 83 percent of the American people—Democrats, Independents, Republicans, Democrats who voted for Reagan, and most of all the group between 18 and 24 years of age, and the middle class and the elderly—who supported that type of legislation.

Then he reached over to the people who would pay the tax, the people who make more than $50,000 a year, and 73 percent of the people who would pay the tax—which would include all of us—said they were in favor of that tax, were in favor of paying it.

If you had $100,000 per year income, you would pay less than $800 into this contribution. And just think what that would mean to the people out there.

So Lou Harris said he has never seen such unanimity among the people in support of a principle as he finds in support of that principle.

The Chairman. Just two other items. Why not let the private sector handle this, private insurance? Why should we have a whole additional Federal program? Why not let the private sector just insure seniors for this kind of care? Why develop a whole new trust fund or savings fund to try and pay for this?

Mr. Pepper. Senator, the reason for it is there are no insurance policies that I know of in the land today that are anything like adequate and within the means of the masses of the people who suffer this kind of disability. I think the way you have constructed the matter is, first, add in the first 6 months under social insurance, and then thereafter they would pay something toward Federal insurance that would enable them to stay in a nursing home for a long time. But until the private insurance system can develop a far better system and get far more coverage—take, for example, Social Security. How much premium would the person ordinarily have to pay if they had a limited membership in the group so that each individual would get an average of over $400 per month who retires? But by having social insurance so that everybody who is earning income pays into that fund, it is not heavy upon anybody, and it is adequate to meet the needs.

So I think when we can, we want to add in private insurance and supplement social insurance with private insurance just as rapidly as we can, and wherever possible, I'd like to see managerial influence of private industry used in the administration of the plan.

The **Chairman**. A final question. Why not means test this? Why should we have the benefits of this program available to those who can afford to pay it? Why not means test it?

Mr. **Pepper**. Senator, our bill provides that a local group in each county where the applicant applies for aid would determine whether or not the family needs the kind of help that the bill would provide. But to establish a means test in the first place is ignominious to many people; it is like Social Security. When a recipient of Social Security goes to the post office and gets his check out, he doesn't mind if the world is looking over his or her shoulder, because he helped pay for that. But if it were a welfare check, thank God most Americans don't want to live on welfare and be the beneficiaries of welfare. But he'd be seeing who is looking over his shoulder to see whether or not he got a welfare check. It is the only fair way, although we can have moderate and modest complement of the social insurance benefits. But the only fair way is for everybody to contribute a little who is eligible to do so to the benefit of those who can't make the contribution.

The **Chairman**. Thank you.

Senator Hatch?

Senator **Hatch**. Thank you.

I just want to again say, Congressman Pepper, it is nice to have you here, and we appreciate having the benefit of your wisdom in this matter.

I do have one comment. I would urge you to ask the House conferees on the Labor/HHS appropriations bill to accept the Senate provision which provides $5 million for health care services in the home. I think this is one important way to help establish this principle this year, and of course, get Americans involved in services in the home.

When we passed that out of this committee, it was $100 million, and it has been whittled down to $5 million, and all it does is provide for demonstration projects in three to five States, but under a complete bill that literally would help solve these problems. I hope you will encourage them to make sure that money is appropriated. It is small enough money, and it would help to prove this case once and for all.

Mr. **Pepper**. Senator, with all respect, sir, as Senator Durenberger said at a hearing I was at over here not long ago, we have had hearings for years here, in the Senate and in the House. We don't need anymore demonstrations. It has been demonstrated every day in heart-rending appeals that are being made to us from the needy people of this country. So let's get on with a substantial accomplishment——

Senator **Hatch**. Maybe I misspoke, or I didn't define it well. It is a full bill that brings home health care now to people. The best I could get out of the Congress was three to five States that participate. It is not a demonstration project. It is an actual project in home health care that will show that it works and will prove it one and for all. When we tried to come up with a comprehensive home health care bill a few years back—and it was comprehensive—it was shot down because the Congressional Budget Office estimated it would cost $3 billion at that particular time. So that's why we've gone this route. It is a complete bill that would help solve this problem and help make the case. So I am just asking for your help.

Mr. PEPPER. Senator, anything that needs to be done and is fair and proper——

Senator HATCH. It would be.

Mr. PEPPER [continuing]. We should all work together to achieve. But this is basically a simple bill. We simply levy a tax of 1.45 percent on incomes above $45,000 and provide the money to take care of these home care needs of the people. In that way, we have been fair to everybody; all the people who pay the tax, someday or another, they may be poor, and they may need the health care, and they will be eligible—just like people who pay into Social Security. Sometimes they pay when they are well off; sometimes they don't have any money left when they get to the period of retirement that they are the beneficiaries of.

It is all right with me to add a little—a little—complement by the person receiving the benefit when they can pay it. But basically, I think we are going to have to approach this thing as a social insurance program just like we have approached Social Security.

Thank you.

Senator HATCH. Well, let me just add one other thing. I appreciate those comments. As you know, we are at the end of this session, so it is unlikely that this bill would pass this year. That bill has already passed; all we have got to do is fund it. And frankly, that would go a long way toward making the case that you are making now—that it really would save us money in the long run to go this route. So that's why I bring it up here today. There is something that is comprehensive, that is good, that really would work, and we can get it through this year. If this type of legislation is what needs to be done, then I think over the next year, we'll all work on it and see what can be done.

Mr. PEPPER. Thank you, Senator.

The CHAIRMAN. The Senator from Ohio, Senator Metzenbaum.

Senator METZENBAUM. Claude, I just want to say to you that you are a walking encyclopedia of facts and information concerning senior citizens.

Mr. PEPPER. Thank you, Senator.

Senator METZENBAUM. It is understandable why you are the single hero of all the senior citizens of this country, and it is just a privilege to be here and listen to you speak. It is just fantastic.

Mr. PEPPER. Well, thank you, Senator. The Lord has been good to me.

The CHAIRMAN. The Senator from Illinois.

OPENING STATEMENT OF SENATOR SIMON

Senator SIMON. I simply want to join in saying that we deeply appreciate your leadership. It was a pleasure to work with you in the House and an honor, but we best pay tribute to you not with flowery words of praise, but by doing the things that you call upon us to do. I am honored to be the chief sponsor in the Senate of your home health care bill. I applaud Senator Kennedy for introducing his bill. It is long past due that we move forward. You don't need another plaque. You don't need another honorary degree. What you want to see is that we do what we ought to be doing for the seniors of this country, and I hope we do it. That's the kind of tribute we ought to pay to Claude Pepper.

Mr. **Pepper**. Well, you know what a privilege it is to be able to work with Senator Kennedy and you and Senator Metzenbaum and others who have worked in this field for so long.

Senator, just let me add this. You know, there is something sort of peculiar in the psychology of the Congress. Every now and then, a move will get started, and it begins to gain momentum and gain force, and great periods of legislative accomplishment come out of it.

Look at the year 1965. After we waited all those years, when Truman asked that we adopt national health insurance and nobody did anything about it; my Committee on Wartime Health and Education made the same recommendation, and Congress did nothing about it; finally, in 1965, we passed Medicare, Medicaid, and the Older Americans Act.

Now, I feel that the time has come, the time is right in the Congress for us to move to accomplish the things that we have worked for for so long in this field. I believe public opinion is behind us. And I put in the record yesterday in the Ways and Means Committee an article from the new U.S. News & World Report, the August 8 issue, which says the main issue in the Presidential campaign that is coming up is going to be long-term care. People are ready for it. They are demanding it today. And I am just glad that we have leaders like you, and that we can work together to try to give it to them.

Thank you, Senator.

Senator **Simon**. Thank you.

[The prepared statement of Senator Simon follows:]

STATEMENT SENATOR PAUl SIMON
on introduction of the
LIFECARE PROGRAM FOR LONG-TERM CARE

AUGUST 3, 1988

Mr. Chairman, I thank you for bringing this critical issue to the attention of the committee. It is an issue that is exploding. I am proud to join you today in sponsoring "Lifecare." This bill will provide a blueprint for how our government should take care of our nation's elderly, sick, physically and mentally ill, and provide for long-term care. Lifecare provides relief for the American family of today and of the future.

The aging of our society has been described as a 20th century miracle. The quality of life for most elderly Americans has improved dramatically over the last quarter of a century. Research and preventive efforts have made all of us healthier. One effect of a healthier America has been increasing numbers of Americans have become elderly and we now must meet the challenges of old age.

When Social Security passed, the average American lived to be 58. We now live to be an average of 75. And very shortly we are going to see an explosion in this demand for long-term care. And we are either going to devastate seniors and families or we are going to meet this problem in a constructive way.

People aged 85 and older are more than 4 times as likely as those aged 65 to 74 to need long-term care services. There is a great need for a comprehensive bill to address the health care needs of our elderly and disabled citizens.

Three months ago I joined Senator George Mitchell in the introduction of a long-term care proposal for the chronically ill. As I indicated then, the proposal does not go as far as I think we should on long-term nursing home care. It troubles me that that plan provides Medicare benefits for nursing home stays once a person had spent two years there; once low- and middle-income elderly have lost everything they worked for. I am here today to build and to improve on past efforts.

Sixty-three percent of patients in nursing homes are there for less than six months. Lifecare provides a minimum of six months coverage. It also establishes a voluntary insurance plan for those over 45, who seek to insure themselves against unlimited, longer stays.

I believe that Lifecare will meet the challenges facing our nation and the aging of our population. For America, Lifecare in the 1990's is what Social Security was in the 1930's and Medicare was in the 1960's. Lifecare will be able to help the American family afford long-term care for their parents, grandparents, relatives, friends and other loved ones without having to sacrifice their own dreams of a home, college education for their children or basic necessities. Long-term care is a family issue, a women's issue, an elderly issue and a disability issue. It is about families who are being devastated by the need for long-term care.

I receive letters from senior citizens asking for help when their spouse is in a nursing home and they have spent their life savings in less than a year and are now forced to go on welfare and receive Medicaid. Last year a gentleman from Greenville, Illinois, starved himself and lived without air conditioning so that his wife could stay in a local nursing home.

Recently, a woman from Riverside, Illinois wrote this:

"A friend of mine, Mary Ingorvato, was recently admitted to a hospital for a broken foot and a cracked chest bone as a result of a fall. After three days, discharge plans were in the making. She was bedridden, and suffered from diarrhea and fever. There was no possible way in which she could care for herself, for she was still ill. The doctor said that she needed further medical care, but was informed that Medicare would no longer cover her hospitalization. Thus, she would have to be released. This seems strange, being that she is allowed sixty days plus on Medicare. Once she was kicked out of the hospital, there would be no one to care for her and she has no money for a nursing home.

After one week at home, she returned to the hospital via ambulance. The diagnozis was two cracked vertebrae. Her spine was deteriorating and after immedicate medical treatement at the hospital it became evident that a nursing facility was the only answer. Medicare does not pay for this and neither does supplemental hospital care. She has no money. Her life savings is now enough for two months in even the lowest cost home. Prior to her health problems, she managed beautifully on $460.00 per month. Additionally, no nursing homes want her. Certain facilitites will not accept public aid patients. In many cases patients must make a $40,000.00 deposit. Caring for senior citizens has become a flourishing business, and it provides a service only the wealthy can afford."

It is a shame that the hard-working, upstanding citizens in our country are reduced to poverty because America lacks a long-term care plan to serve the very basic need for adequate health care and related medical services.

I ask for support on this very important issue today and hope that we can address this great need before the 100th session ends.

We must ensure that all Americans share in the dignity of our nation and that a dignified nation--a dignified America--cares for our aging, disabled and mentally ill citizens. This is not a burden. It is the just and right thing to do.

The **CHAIRMAN**. Well, we again want to say how appreciative we are to have you come over and make this case. It is done very effectively each and every time. I have heard you many times and always benefit from hearing you again.

You take care of young Joe Kennedy over there, now.

Mr. **PEPPER**. Well, Senator, yesterday, young Joe and I held a hearing in Boston, and we would be happy to give to you this T-shirt, "Home Care is the Best Care." So I'll give it to you today.

The **CHAIRMAN**. All right. It will be a delayed birthday present to my mother, who was 98 years young last week.

Thank you very much, Claude.

Mr. **PEPPER**. Thank you very much.

The **CHAIRMAN**. I would like to now welcome to our hearing and invite them to come to the witness table three witnesses who will be able to portray for us, from their own personal lives, the kind of situations our legislation is intended to help address. They have been gracious and generous to be willing to give of their time and their personal experience to tell us some of the kinds of things which, although often painful to talk about and even to hear, we must listen to and pay close attention to if we truly want to make a difference in providing comfort and support at a critical time in the lives of the American families.

We will hear first from Mrs. Albert Develle from Tampa, FL, who has been trying for some time to care for her ailing mother, who is now in a nursing home.

Then we will hear from Mr. William Gibbons, from Rockville, MD and his really heroic efforts to care for his ailing wife of many, many years.

And then we will hear from Estelle Powlovich from Greenfield, MA, a widow who, despite her illness, is trying to live at home while she is still leading a productive and fulfilling life.

We welcome all of you here and look forward to your testimony.

Mrs. Develle, why don't you begin?

STATEMENTS OF MRS. ALBERT DEVELLE, TAMPA, FL; WILLIAM J. GIBBONS, ROCKVILLE, MD; AND ESTELLE POWLOVICH, GREENFIELD, MA

Mrs. **DEVELLE**. Mr. Chairman and members of the committee, I am here on behalf of my mother today, Julienne Chadwick, who is 74 years old and a victim of Alzheimer's.

In 1985, she had a small stroke and was hospitalized. Prior to her hospitalization, she had been undergoing tests for abnormal behavior patterns. During her treatment for the stroke, the neurologist did further testing and then advised us of her condition and our future in caring for her.

Upon her release from the hospital, and knowing that she could not care for herself anymore, we brought her to live with us. At that time, both my husband and I worked, and it was necessary to hire two caregivers, working from 7 a.m. to 6 p.m. Within a very short period of time, she began not sleeping at night and roamed the apartment, lost, confused, frightened, and constantly undressing herself.

This brought on crying and screaming spells, necessitating that I stay up with her to try and calm her. After weeks of no sleep and being on the verge of a collapse, we added another caregiver, making round-the-clock shifts of 24 hours.

This worked for about a year, until she became so hostile and aggressive, she threatened all of us. She was also incontinent at this time.

The strain of all this began to take its toll on my husband and I, and our home life had become very stressful.

In October 1986, we had no alternative but to place her in a nursing home.

This debilitating and heart-breaking disease is burden enough for anyone, but to see not only her assets, and now ours as well, disappearing as rapidly as her mental capabilities is a nightmare that we have to live with 24 hours a day, with our emotions crying out to anyone and everyone to please, somebody, help us.

My mother receives $450 Social Security pension; $707 VA pension, which is a widow's pension; and $26.38 of private retirement pension, which is a total of $1,183 per month. These Government benefits she is receiving are keeping her from qualifying for Medicaid, because she is $253 over the Medicaid allowance, which is $913.

Because of these Government restrictions, she will never qualify for Medicaid benefits. Her monthly expenses are: $2,160 a month for nursing home; $120 for drugs, which is an average; $105 for miscellaneous, which includes wipes, restraints, et cetera; and $86 for Blue Cross/Blue Shield payments—which is a total of $2,471. When you subtract this from the $1,183 she gets, it leaves a shortage of $1,287 a month.

We are now using our retirement savings to make up this shortage each month, and we estimate that in 5 to 6 months, that will be gone.

At that point, we are wondering what is going to happen to us—and not only that, but what is going to happen to my mother?

All of this is our living nightmare, every single moment of every single day. It is the last thing you think about when you go to bed and the first thing you think about when you wake up in the morning.

Why are the reliable, stable, middle-income groups being sacrificed? Is it discrimination when you have too much income to meet Medicaid limits, but too little income to meet medical bills, which drive you to bankruptcy? Can it be because of the potential long-term confinement, we willingly sacrifice the lives and futures of the families of the afflicted?

The suffering and degeneration of these people's minds is painful enough, but must they also endure the humiliation of a "snake pit" environment when their funds run out?

We desperately need Congress to pass a bill approving payments for nursing home care. And I am personally begging this Committee to back this bill and get it passed.

I would just like to add one more thing, that were it not for the empathy and concern of such people as Senator Kennedy, Congressman Pepper, Congressman Bilirakis, and local individuals like Helen Stevens, who is an attorney in Fort Myers for the Florida

Rural Legal Services, who gave me so much encouragement, I would not have had the opportunity to address this committee.

Thank you.

[The prepared statement of Mrs. Develle follows:]

PREPARED STATEMENT OF MRS. ALBERT DEVELLE

My mother, Julienne L. Chadwick, is 74 years old and a victim of Alzheimer's. In 1985 she had a small stroke and was hospitalized. During the previous six months she had been undergoing tests for unusual behavorial patterns. During her treatment for the stroke - the neurologist did further testing and then advised us of her condition and our future in caring for her.

Upon her release from the hospital, we brought her to live with us. At that time, both my husband and I worked and it was necessary to hire two (2) caregivers - working from 7 a.m. to 6 p.m. Within a very short period of time, she began not sleeping at night and roamed the apartment lost, confused, frightened and constantly undressing herself. This brought on crying and screaming spells necessitating that I stay up with her to try and calm her. After weeks of no sleep and being on the verge of collapse, we added another caregiver making round the clock - 24 hr shifts. This worked for about a year until she became so hostile and aggressive she threatened all of us. She was also incontinent at this time. The strain of all this began to take its toll on my husband and I and our home-life had become very stressful.

In October of '86 we had no alternative but to place her in a nursing home. This debilitating and heartbreaking disease is burden enough for anyone but to see not only her assets but now ours as well disappearing as rapidly as her mental capabilities is a nightmare we have to live with 24 hours a day - with our emotions crying out to anyone and everyone - "PLEASE, SOMEBODY HELP US!"

My mother receives

$450.00	Social Security
707.00	VA Pension - Widows
26.38	Pvt. Retirement Pension
$1183.38	

These government benefits she is receiving are keeping her from qualifying for Medicaid because she is $253.00 over the Medicaid allowance (which is $913.00). And because of these government restrictions she will never qualify for any Medicaid benefits.

Her monthly expenses are -

$2160.00	Nursing Home (72/day x 30
120.00	Drugs (avg. month)
105.00	Mis. (wipes, drapes, restraints)
86.00	Blue Cross/Blue Shield
$2471.00	Total
- 1183.38	Income
$1287.62	Shortage

We are now using our retirement savings to make-up this shortage each month and we estimate that in 5-6 months that will be gone. At that point - what happens to us or better yet - what happens to my mother!!! All of this is our living nightmare every single moment of every single day.

Why are the reliable, stable, middle income group being sacrificed?

Is it discrimination when you have too much income to meet Medicaid limits - but too little income to meet medical bills which drive you to bankruptcy.

Can it be because of the potential long-term confinement we willingly sacrifice the lives and futures of the families of the afflicted.

The suffering and degeneration of their minds is painful enough - but must they also endure the humiliation of a "snake pit" environment when their funds run out?

We desperately need Congress to pass a Bill approving payments for nursing home care. And I am personally begging this committee to back this Bill.

Were it not for the empathy and concern of such people as Senator Kennedy, Congressman Claude Pepper, Senator Bilirakis and local individuals like Helen Stevens, attorney for Florida Rural Legal services and who gave me so much encouragement, I would not have had the opportunity to address this committe today.

The **Chairman**. Thank you very, very much, Mrs. Develle.

We will now hear from Mr. Gibbons.

Mr. **Gibbons**. Mr. Chairman and members of the committee. My name is William J. Gibbons, of Rockville, MD. I was born in Woodford County, IL 76 years ago.

I am a lawyer by training and occupation. After having spent some 30 years in the Federal Government as an attorney and an administrative law judge, I retired from the Interstate Commerce Commission in 1976. Following that, I did some part-time work for the Small Business Administration and taught Business Law at Montgomery College, in Montgomery County, MD.

Unfortunately, I had to quit—was forced to quit—those activities because of the ill health of my wife.

My present Civil Service annuity is $3,200 a month, and my wife's is $475 per month.

She is 78 years old, and has been suffering from Parkinson's disease since about 1970. When first diagnosed, her condition was moderately severe, but over the years, it has become progressively worse, and now it may be characterized, I think, as extremely severe.

She is homebound, uses a wheelchair most of the time, can't walk except maybe a step or two now and then. Her symptoms include tremors, rigidity, loss of speech, slurred speech, exhaustion, sometimes constipation, sometimes incontinence, uncontrolled muscular movements, confusion, and hallucinations.

Besides, her overall condition is compounded by numerous other ailments that she has, including Pagett's disease, the residuals of a fractured femur and a fractured arm. More recently, she was found to have breast cancer, had a modified mastectomy, and presently takes medication, Tamoxifen, to prevent or slow down the cancer growth.

We have Blue Cross/Blue Shield, Standard Option, and Medicare Part B. Blue Cross pays all of the costs of prescription medicine. Part B Medicare pays 80 percent of such things as doctors' services, diagnostic tests, and prosthetic devices, and several other things. But there are numerous devices and services that neither Blue Cross nor Part B pays for, such as eyeglasses, hearing aids, nursing home care, home health care, dentures, orthopedic shoes, incontinence supplies, dietary foods, and private duty nursing.

My wife has needed many of those items during the latter part of 1987 and the first part of 1988. Probably, the bill will reach at least $10,000 in 1988 for those necessities that are not covered by insurance.

In early 1988, I hired a registered nurse to care for my wife immediately after her release from hospitalization for cancer operation. That was a period during which she had considerable pain, and a night duty nurse was deemed necessary.

Then I hired a nurse technician who is still with us; she cared for Lucille 5 days a week, 5 hours a day, at $200 a week. For the other 19 hours in the day, I take care of my wife the best way I can. So far, we have been able to keep our heads above water financially after dipping into savings.

But now, my wife needs another nurse technician at home, or nursing home care, and I need some respite from my nursing duties. With this added expense, health costs will become a very heavy drain on me, become almost prohibitive, unless we get some medical assistance beyond what presently exists.

For long-term nursing home care and home health care, the only recource at present is Medicaid. Private insurance, as has been pointed out, is wholly and totally inadequate. And Medicaid is also inadequate for certain groups of people, particularly for the middle-income people who, to qualify for Medicaid, must meet certain income and asset levels. With reference to nursing home care, this means that they have to impoverish themselves by paying for the necessary care out of their savings until such time as they have used all or most of their resources.

This is known as the spend-down process, which every State has, but which differs from one State to another.

There is another method of spending-down, but I wanted to highlight this one, which involves, buying your way into a nursing home.

Most of the information that I have concerning the spend-down maneuver was obtained from a 1987 publication of Johnson & Johnson called Medicaid.

Changes in the new Federal health law affecting spend-down requirements are deminimis.

Now, at $100 a day—and that is what some nursing homes are charging—and with certain options, luxuries, and incidentals, it doesn't take very long to spend down or go through all of your life savings. This creates a hardship on everybody concerned, especially for a noninstitutionalized spouse who is at home, living a hand-to-mouth existence, under circumstances that are completely beyond his or her control. In my humble opinion, this becomes almost catastrophic.

The CHAIRMAN. Mr. Gibbons, I'll give you another minute. We are going to have to go over and vote.

Mr. GIBBONS. All right. All I have to say is that I am greatly in need, and there are thousands, hundreds of thousands more out there in dire need of medical and financial relief, and this relief must and will come through an act of God or an act of Congress or a combination of both. While this will be a costly program, it will pale into insignificance compared to the astronomical sums that "We the People" spend annually on unnecessary and frivolous programs. Besides, the cost of the program can be defrayed or partially offset by premium payments and the possibility of making coverage mandatory and universal should be considered for the purpose of generating more premiums, thus affording equal long-term health care protection to every man, woman, and child in America. I strongly support the legislative proposals of Senator Kennedy, and also want to thank this Committee for the opportunity to express my views.

The CHAIRMAN. Thank you very much.

[The prepared statement of Mr. Gibbons follows:]

PREPARED STATEMENT OF WILLIAM J. GIBBONS

Mr Chairman and members of the Committee

My name is William J. Gibbons, 15808 Sycamore Lane, Rockville, Maryland 20853.

Born November 14, 1911 in Woodford County, Illinois. Age 76; Graduated from St. Viator College, Bourbonnais, Illinois, and from Georgetown University Law School; LLM from the University of San Francisco; Member of the Illinois Bar.

After some 30 years service as an attorney and administrative Law Judge, I retired from the Interstate Commerce Commission in January, 1976. My present civil service annuity is about $3,200 a month, and my wife's, about $475 a month. For about 4 years following retirement, I did some part-time work for the Small Busines Administration, and taught business law at Montgomery College in Maryland. Quit because of wife's health. ¶ My wife (Lucille) who is 78 years old has been suffering from Parkinson's disease since 1970. When first diagnosed, her condition was moderate but over the years it became progressively worse and may now be characterized as extremely severe. She is homebound, unable to walk, and uses a wheel chair most of the time. Her symptoms are tremors, rigidity, loss of voice, slurred speech, exhaustion, sometimes constipation, sometimes incontinence, uncontrolled muscular movement, confusion and hallucinations. 1/

1/ She takes 6 Sinemet in a 24 hour period.

Her overall condition is compounded by numerous other ailments, including Pagett's disease, and the residuals of a fractured femur and arm. More recently she had breast cancer, had a modified mastectomy and presently takes medicine (Tamoxifen) designed to prevent or slow down the spread of cancer.

We have Blue-Cross Blue-Shield, Standard Option, and Medicare Part B. Blue Cross pays the total cost of prescription medicine. Part B Medicare pays 80% of such things as doctors' services, diagnostic tests, and Prosthetic devices. But there are numerous things that neither Blue Cross nor Part B pays for, such as eye glasses, hearing aids, tooth extractions, and dentures; long-term nursing home care and home health care; orthopedic shoes, incontinent supplies and dietary foods; and private duty nursing. My wife has needed many of these uncovered items in the latter part of 1987 and in 1988.

In early 1988, I hired a registered nurse to care for my wife after her cancer operation. That was night duty for about a week. At the same time, I hired a nurse technician for day duty. She is still taking care of my wife 5 days a week, 5 hours a day, at a cost of $200 a week. For the other 19 hours a day, I care for my wife the best I can, acting as the chief cook and bottle washer, doctor, nurse and spiritual adviser. So far, after dipping into savings, I've been able to keep my head above water financially, but at this point, my wife needs another nurse technician, or nursing home care, TB2

and I need some [respite from my nursing duties. With this added expense, health costs] may very well become prohibitive unless we get some medical assistance beyond what presently exists.

For long-term nursing home care and home health ~~home~~ care, our only resource at present is Medicaid. Private insurance is wholly and woefully inadequate. It can also be said that Medicaid is inadequate for the middle income people, because to qualify for Medicaid help it is necessary to meet certain income and asset levels - which means that a person must become poor by paying for necessary nursing home care out of his or her income and savings.[2/] This is known as the spend down process which differs to some extent from one state to another. At $100 a day for nursing home care, with extra charges for options, luxuries, and other incidentals, it doesn't take long to "spend down" or go through a whole life savings. This is quite disruptive especially for the non-institutionalized spouse who must live a hand-to-mouth existence at home under circumstances completely beyond his or her control. In my humble opinion, this situation comes close to being catastrophic.

There has to be a better alternative to Medicaid insofar as it relates to long-term health care. For thousands - even hundreds of thousands of middle income persons or those with sizeable savings who cannot afford the cost of long-term

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[2/] In 1987, in Maryland the eligibility level for an individual was $4000 a year in income and $2500 in resources.

health care or are emotionally disinclined to play the "spend down" game, relief must come in the form of financial assistance - this through an act of God or an Act of Congress, or both. While this will be a costly program, it would pale in to insignificance compared to the astronomical sums that "We the People" spend annually on unnecessary, and frivolous programs. Besides the cost of the program could be defrayed or partially offset by premium payments and the possibility of making coverage mandatory should be considered.

I strongly support the proposals of this Committee regarding long-term health care, and thank you for the opportunity of expressing my views.

The **Chairman**. Mrs. Powlovich, if you will be patient enough to give us about 7 or 8 minutes to go over and vote, then we will come back and listen to your testimony. You have all been extremely kind and patient during the course of the hearing. You have a very, very interesting story to tell us; I am familiar with it, and it is going to be very important for our record and for our colleagues to hear about it.

So we'll recess until we have a chance to go over and vote.

Thank you.

[Recess.]

The **Chairman**. We'll come to order.

Mrs. Powlovich, we are delighted to welcome you here to the Committee, and I look forward to hearing from you.

Mrs. **Powlovich**. Thank you.

I really am happy to see all these nice people.

My name is Estelle Powlovich. I am 66, and I live alone, in my own home, in Greenfield, which is a small town in western Massachusetts.

Sixteen years ago, I was diagnosed as having Multiple Sclerosis. I continued to work at TRW as the office supervisor. TRW is a toolmaking company. I had worked there for 25 years, and in 1979 I really was going downhill, so I decided I would leave and be able to walk out and not be carried out.

So I gave my resignation and told them that I was going to join the Rockettes at Radio City Music Hall, and that I would be the third from the left, kicking the highest—because I would not let this MS get the better of me—but I think it has!

After I left TRW, I worked as a volunteer teacher in the elementary and junior high schools in Greenfield, and right now, I am doing mostly tutoring in my own home because I'm determined on keeping busy.

My life changed five years ago when I lost my husband. Six weeks after he passed away, a social worker came to my home and suggested that I contact Franklin County Home Care, which I did. The social worker arranged services for me.

Three years ago, the cost of home care rose tremendously.

[Pause.]

The **Chairman**. You are doing awfully well, Mrs. Powlovich.

Mrs. **Powlovich**. This humidity is making me uncomfortable. I'll continue in a moment.

The **Chairman**. I know. There is a great deal of humidity down here. You are doing fine. Just take your time, now, because this is an important part of your testimony as to what has happened with the Franklin County Home Care Program and what a difference it made to you. That is what we would like to hear a little from you about; I understand that you were able to use that, and it made some difference to you.

Mrs. **Powlovich**. After a fall, a visiting nurse came to my home and suggested that I call Franklin County Home Care, which I did. The nurse came over and gave me a shower and talked and helped me get dressed. I felt much more comfortable.

It is so humiliating sometimes when you cannot do for yourself.

Right now, I receive a total of 17 hours a week of home care, paid for almost completely by the State-funded Home care. Because of my income of almost $10,500 a year, I pay a modest sliding fee. I also privately pay for an additional 9 hours of care. Basically, this care amounts to someone coming in the morning to help me to get washed, dressed, and fix a brunch.

One afternoon a week, I have someone who comes in; does my shopping, does the laundry, and cleans the house. I am very fussy and things have to be just right.

Another homemaker comes in the early evening to help me get ready for bed. I am 66, but I am not ready to go to bed at 5:30 when they come, but I have to.

I also receive great transportation service from the Franklin Regional Transit Authority [FRTA].

Without these services I would not be able to live at home. I would have to be in a nursing home. It would even be difficult for me to live with my married son who lives with his wife and family about an hour and a half away.

Why do I struggle to live at home? First of all, I enjoy my own environment, surrounded by my belongings. I enjoy my independence and the ability to come and go as I please. I like having visitors and friends when I want to.

It is important for you to realize that I am a human being just like you. Even though I can't walk, I'm no different than you are. I am very sensitive and proud. It is also important for me to function on my own level in ways that are fully as meaningful and productive as those employed be persons without restrictions—to know that my value as a person is not diminished by circumstances beyond my control. I continue to tutor students in my home and look for other ways to be useful. I am grateful for this opportunity to testify before this committee in such an important cause.

Is the system of help set up for me perfect? By no means. I could use more man-hours of help. Although many of my homemakers and health aides have been and are wonderful, I would like all the help to be qualified and sensitive to the elderly and disabled. It's not easy being dependent on others, having people going through my personal things and not taking caring enough. I am frustrated at times when the help is late or is inadequately trained or insensitive or rushed. More money needs to be spent to train and reimburse good help as well as provide more hours so they won't be so rushed.

Nevertheless, I want to emphasize that I could never live at home without the help I receive. Home care has made the difference.

Thank you for this opportunity to speak to you about my situation.

[The prepared statement of Mrs. Powlovich follows:]

STATEMENT OF
ESTELLE POWLOVICH

My name is Estelle Powlovich. I am a 66 year-old woman living alone in my own home in Greenfield, a small city in Western Massachusetts. Sixteen years ago I developed Multiple Sclerosis. I continued to work as a supervisor at TRW, a tool making company, where I had worked for 25 years. In 1979 I decided I needed to retire because I was using my canes and required an escort to the ladies' room. I told them at my retirement that I was quitting to join the Rockettes at Radio City Music Hall. If they came to see me I would be the third from the left, kicking the highest.

After my retirement, I continued working as a volunteer tutoring in the elementary and junior high schools in town.

My life changed five years ago when my husband died suddenly. For six weeks the social worker from the hospital arranged services for me. I thought I would be lucky to stay alone in my home for a year. But I'm stubborn. I hired private help in the mornings and on weekends to assist me with bathing and dressing. I began to use a wheelchair almost constantly because I was afraid of falling and not being able to get up.

About three years ago the cost of this private help rose dramatically. After a fall a visiting nurse suggested that I call Franklin County Home Care. I did and the home care nurse came right over and helped me take a shower and get dressed.

Right now I receive a total of seventeen hours a week of home care paid for almost completely by the state-funded home care. Because of my income of almost $10,500 a year I pay a modest sliding fee. I also privately pay for an additional nine hours of care. Basically this care amounts to someone coming in in the morning to help me to help me get up to the bathroom, washed, dressed and fix a brunch. Someone comes in in the afternoon to do housework, laundry, shopping and other errands. Another homemaker comes in the early evening to help me get ready for bed. I also receive great transportation services from the Franklin Regional Transit Authority. Without these services I would not be able to live at home. I would have to be in a nursing home. It would even be difficult for me to live with my married son who lives with his wife and son about 1 1/2 hours away.

Why do I struggle to live at home? First of all I enjoy my own environment, surrounded by my belongings. I enjoy my privacy and the ability to come and go as I please. I like having visitors and friends when I want to.

It is important for you to realize that I am a human being just like you. Even though I can't walk, I'm no different than you are. I am very sensitive and proud. It is also important for me to function on my own level in ways that are fully as meaningful and productive as those employed by persons without restrictions, to know that my value as a person is not diminished by circumstances beyond my control. I continue to tutor students in my home and look for other ways to be useful. I am grateful for this chance to testify before this committee in such an important cause.

Is the system of help set up for me perfect? By no means. I could use more time for help. Although many of my homemakers and health aides have been and are wonderful. I would like all the help to be qualified and sensitive to the elderly and disabled. It's not easy being dependent on others, having people going through my personal things and not caring enough. I am frustrated at times when the help is late or incompetent or insensitive or rushed.

. Nevertheless I want to emphasize that I could never live at home without the help I receive and I am grateful to have. Thank you for this opportunity to speak to you about my situation.

The **Chairman**. Maybe I can ask you just a few questions.

I understand you still tutor children in your home.

Mrs. **Powlovich**. Yes, reading and math. I have one boy in geography and history.

The **Chairman**. So you have worked your lifetime, and now you still tutor children in your home.

Mrs. **Powlovich**. I hope I can keep it up, really.

And I want to apologize. Because I am very hot, and I was hoping I would be a little more dynamic! We need that bill so badly!

The **Chairman**. You have done beautifully. You have been awfully good to come all the way down here to tell us your story. I just want to ask you one question. If you didn't have those visitors who come to your home and who help you do the thing which you have told us about here, would you be able to remain at home, or are they really indispensable?

Mrs. **Powlovich**. Yes, to me they are indispensable. I do not want to go to a nursing home.

The **Chairman**. So they are just indispensable to you.

Mrs. **Powlovich**. Yes.

The **Chairman**. And we see what a difference it can make by providing those kinds of services to you a few hours a week, but at very important times, in the morning, and then coming back in the evening and providing those services in terms of going out once a week and helping to clean your home, picking up food, doing the errands. It is absolutely indispensable.

Mrs. **Powlovich**. Yes, it is.

The **Chairman**. And I think we can see that without it, you would have to go to a nursing home.

Mrs. **Powlovich**. Yes. I can't even say that word; I detest it. "Nursing home"—oh, no!

The **Chairman**. Well, you have set an extraordinary example of personal courage and selflessness in terms of trying to help other people as well, and I think you are a real inspiration.

I know that for all of our panelists it is difficult to talk about these matters.

Mrs. **Powlovich**. And I am very proud; I really am very proud, but I am sensitive, also.

The **Chairman**. Well, you have clearly got a good sense of humor, and we are delighted to have you.

I want to tell all of us how much we appreciate your coming here and visiting with us and telling these stories. These are stories of basically middle-America, men and women who have worked over the course of their lives, have continued to work, continued to devote their energies to their communities, have served our country in different capacities, and who have an extraordinary sense of pride and dignity, both in themselves and in the people they love and are faced with these enormous personal challenges of how to make ends meet.

Sometimes, if we provide those services like the visiting nurse program, that is called a spending program. It is not; it is basically an investment in the quality of life of our people, and it is a real indication of our sense of humanity and whether we really care about our fellow citizens. That is really what we are talking about.

I want to thank all of you very much for being here with us this morning. I know we have extended all of your time, but I think you make the case much more clearly than any explanation of the bill. You have pointed out what the needs are in very human terms. And I think it is important, as we know so well, that these aren't isolated incidences; they are taking place in every community in this country. I think the best way we can show our appreciation for your presence here is to try and get this legislation enacted, and I am certainly going to do everything I possibly can to see that that is done.

Mrs. POWLOVICH. And thank you for the opportunity to meet you alone. That, to me, was something—and all those Senators here. I was overwhelmed, because I see them on television---

The CHAIRMAN. Well, you have overwhelmed all of us. Do you know Buster Rigari up there in Greenfield?

Mrs. POWLOVICH. Of course, I do.

The CHAIRMAN. Well, you say hello to Buster when you get back up there. Tell him I'm on the job down here.

Thanks an awful lot for your appearance here. We really appreciate very, very much your coming. Thanks an awful lot.

We will now welcome our third and final panel, which consists of a distinguished group of experts. Mr. Paul Lanzikos is Commissioner for Elderly Affairs, State of Massachusetts, director of one of the best and most comprehensive home care programs in the country; Dr. William Weissert is one of the most widely-respected experts in long-term care, and is Professor of Health Policy and Administration and Director of the Program on Aging at the School of Public Health, University of North Carolina at Chapel Hill; and Arthur Lifson is Vice President of the EQUICOR Corporation, and is presenting the views of the Health Insurance Association of America.

We'll start off with you, Paul.

STATEMENTS OF PAUL J. LANZIKOS, SECRETARY, EXECUTIVE OFFICE OF ELDERLY AFFAIRS, BOSTON, MA; DR. WILLIAM WEISSERT, DIRECTOR, PROGRAM ON AGING, SCHOOL OF PUBLIC HEALTH, UNIVERSITY OF NORTH CAROLINA, CHAPEL HILL, NC; AND ARTHUR LIFSON, VICE PRESIDENT, GOVERNMENT RELATIONS, EQUICOR, INC., ON BEHALF OF HEALTH INSURANCE ASSOCIATION OF AMERICA

Mr. LANZIKOS. Thank you, Senator, and good afternoon.

If I may begin on a personal note, during my entire professional life, I have been devoted to working for, in behalf of, and with, older people. And one of my heroes, one of my inspirations, through that entire time has been Senator and Congressman Claude Pepper. In fact, his advocacy and toiling began before I was born in behalf of older people.

Earlier this week, I had the privilege of testifying before him and your nephew in Boston, and now, today, joining him on this witness panel, I'd like to thank you, Senator, for making this one of the special weeks in my professional career, being associated now twice in 1 week with Senator Claude Pepper.

In addition to my prepared comments, submitted to you and the committee, I have also included a statement from the National Association of State Units on Aging on Long-Term Care. It is a comprehensive position paper on long-term care that was drafted and released in June at our annual meeting.

My professional background, in addition to being a public administrator of a major community-based State program of care, includes service as a nursing home administrator and an executive of a community hospital in Massachusetts. So I have had a number of opportunities and ways to see professionally, as well as personally, in my own family, the issues and also the opportunities that are afforded in our system.

In many ways, long-term care, while it is very simple and straightforward, is perhaps one of the most perplexing and confusing systems in our society today. In many ways, it is like the Rubic's Cube; in fact, it doesn't have just three sides or three sets of cubes; it has nine and twelve and exponentially growing. And the demographics and changes in Medicare and Medicaid, technological advances and pharmaceutical advances are making it even all the more confusing; and lifestyle changes in our families are adding further to the dimension of that confusion.

One of the things that impresses me in your legislation as proposed is that you look at long-term care as not being just a straightforward system of services, but rather, recognizing that there are many national and State and local policies that have to be intertwined, and those include at least five components that we have been working on in Massachusetts in our comprehensive policy. That includes housing policy, which you have addressed in your legislation; and the need for home medical care and home functional support services; and the fourth is institutional long-term care; and the fifth is acute care, including doctors' offices, emergency rooms, and mental health services.

For at least the last two decades, the burden of organizing and delivering this system of long-term care has fallen to the States. And I would say in large part we have done a commendable job, but because of increasing pressures, we now need to look to the Federal Government for that national leadership and additional resources. I commend you and Congressman Pepper and other members of this committee and Members of Congress for bringing this important issue before us legislatively.

As you know, in Massachusetts, we have long been a leader in community care. In fact, one of the building blocks in your proposal is the case management system which, over the last 14 years, we have been developing. And case managers really are at the root of effective system of services for elderly people, disabled people of all ages and their families, where we can take a national policy and State organization and bring it down to individual interpretations for folks like Mrs. Powlovich, who just testified before I did.

We still have many issues before us. At least three challenges are in the wings. The need for trained, effective workers—in fact, I am pleased to see that technical assistance and training are such an integral part of your proposal—the need for standards that have to be in place to assure that the system is doing the job it is supposed to be doing and making sure those standards are met; and lastly, the integration of all the services among all provider entities, and not just having one aspect of the system trying at the expense of other parts of the system.

I commend you for a proposal that is cost effective, efficient, and reasonably simple. I think that is important, because this is a very complex, often emotionally demanding, area, as we have witnessed here already this morning. And additional complexities and confusion just add to the problems instead of helping. The access to care and universality of coverage are extremely important.

I am confident that with the abilities we have at the State level and our providers in communities throughout the Nation, in conjunction with the type of leadership and resources that are envisioned in your proposal, that we can do the job of bringing effective community care to families throughout America. We cannot do it alone, and we surely cannot allow the long-term care system to be solved at the expense of elders and disabled people throughout this country. The States have been the working laboratory. Let's take what we know has been a result of that working laboratory and get the job done. Now is the time to do it, and we commend you for your leadership.

The CHAIRMAN. Thank you very much.

[The prepared statement of Mr. Lanzikos, with an attachment, follows:]

TESTIMONY OF

PAUL J. LANZIKOS

SECRETARY

EXECUTIVE OFFICE OF ELDER AFFAIRS

COMMONWEALTH OF MASSACHUSETTS

BEFORE

SENATE LABOR AND HUMAN RESOURCES COMMITTEE

LONG TERM CARE HEARING

AUGUST 3, 1988

CHAIRMAN KENNEDY AND MEMBERS OF THE COMMITTEE, THANK YOU FOR THE OPPORTUNITY TO TESTIFY HERE TODAY AND CONGRATULATIONS, SENATOR KENNEDY, FOR FILING COMPREHENSIVE LEGISLATION ADDRESSING THE LONG TERM CARE NEEDS OF MILLIONS OF AMERICANS.

I HAVE EXPERIENCED THE SUCCESSES AND FAILURES OF OUR CURRENT LONG TERM CARE SYSTEM FROM SEVERAL PERSPECTIVES--AS AN ADMINISTRATOR IN A NURSING HOME, AS AN EXECUTIVE IN A COMMUNITY HOSPITAL, AND NOW AS DIRECTOR OF A MAJOR COMMUNITY CARE SYSTEM.

I'VE SEEN THE HARDSHIP THAT THE COST OF NURSING HOME CARE IMPOSES ON FAMILIES AND SPOUSES WHO HAVE TO PAY FOR IT. I'VE SEEN THE CHALLENGES HOSPITALS STAFF FACE TRYING TO BLEND ACUTE AND CHRONIC CARE, INPATIENT AND COMMUNITY CARE FOR PEOPLE CAUGHT IN A SYSTEM THAT OFTEN FAILS TO PAY FOR A CONTINUUM OF CARE, AND A DELIVERY SYSTEM THAT IS FAR TOO COMPLICATED TO COORDINATE FOR OF PEOPLE LEAVING THE HOSPITAL.

AS SECRETARY OF ONE OF THE NATION'S LARGEST COMMUNITY CARE SYSTEMS, I'VE SEEN THE SUCCESSES, THE POTENTIAL AND THE CHALLENGES OF COMMUNITY CARE.

STATES HAVE DONE A COMMENDABLE JOB DEVELOPING COMMUNITY CARE SYSTEMS AND ATTEMPTING TO COVER THE CATASTROPHIC COSTS OF PROLONGED NURSING HOME STAYS THROUGH MEDICAID. BUT OFFERING A TRULY COMPREHENSIVE, AFFORDABLE PROGRAM IS BEYOND THE CAPACITY OF STATES TO HANDLE ALONE.

THE LONG TERM CARE "SYSTEM" IS REALLY A PATCHWORK OF FUNDING STREAMS, AND SERVICES, HELD TOGETHER BY FAMILIES. IN MASSACHUSETTS, WE OFFER CASE MANAGEMENT SERVICES TO HELP FAMILIES SORT THROUGH THIS MAZE; WE PROVIDE $128 MILLION IN STATE FUNDED SERVICES FOR COMMUNITY CARE AND THROUGH OUR MEDICAID PROGRAM, PAY OVER $700 MILLION FOR NURSING HOME AND COMMUNITY CARE. BUT WE ACKNOWLEDGE THAT FINANCING FOR LONG TERM CARE REQUIRES OVERHAUL.

IN THE ABSENCE OF A STRONG FEDERAL POLICY, MASSACHUSETTS HAS BEGUN A PLANNING EFFORT TO ASSURE THAT LONG TERM CARE COVERAGE WILL BE AVAILABLE IN THE 1990s. JOINTLY FUNDED BY THE ROBERT WOOD JOHNSON FOUNDATION AND THE STATE, THE PLANNING PROJECT HAS IDENTIFIED FIVE GOALS THAT ANY NEW FINANCING APPROACH MUST ADDRESS: THE SYSTEM MUST BE AFFORDABLE, OFFER EQUAL ACCESS AND UNIVERSAL PARTICIPATION, ASSURE QUALITY CARE AND LASTLY, IT SHOULD SIMPLIFY NOT COMPLICATE THE CURRENT SYSTEM. OUR WORK IS PRELIMINARY, AND WE WELCOME THE GROWING INTEREST AMONG MEMBERS OF CONGRESS TO CAST THE FEDERAL GOVERNMENT AS A MAJOR PARTNER IN THE EFFORT TO DEAL WITH LONG TERM CARE.

COMMUNITY CARE IN MASSACHUSETTS

I'D LIKE TO FOCUS THE REST OF MY REMARKS ON THE COMMUNITY CARE COMPONENT. THE EXECUTIVE OFFICE OF ELDER AFFAIRS IS A CABINET LEVEL AGENCY THAT ADMINISTERS A $128 MILLION STATE FUNDED, IN-HOME SERVICES PROGRAM FOR FRAIL ELDERS. WE CONTRACT

WITH 27 LOCAL, NON-PROFIT HOME CARE CORPORATIONS WHO OPERATE ON A FIXED BUDGET. THE HOME CARE CORPORATIONS ARE LOCALLY GOVERNED AND A MAJORITY OF THEIR BOARD MEMBERS ARE ELDERS.

THE HOME CARE CORPORATIONS PROVIDE CASE MANAGEMENT. EXCEPT IN SPECIAL CIRCUMSTANCES, THEY DO NOT PROVIDE DIRECT SERVICES. THEY ARE AN INDEPENDENT CASE MANAGEMENT AGENCY.

WHO DO THEY SERVE? I RECENTLY WENT WITH A CASE MANAGER TO SEE AN 85 YEAR OLD WOMAN. SHE LIVES ALONE, LIKE 70% OF THE NEARLY 44,000 PEOPLE SERVED EACH MONTH. A NEIGHBOR WAS WORRIED ABOUT HER AND MADE THE REFERRAL.

THE CASE MANAGER COMPLETED THE STANDARDIZED NEEDS ASSESSMENT THAT MEASURES FUNCTIONAL IMPAIRMENTS, RECORDS HEALTH CONDITIONS AND MEDICATIONS, DETERMINES WHO IS AVAILABLE TO HELP HER, WHAT OTHER SERVICES SHE MAY RECEIVE, WHO IS THE DOCTOR AND WHEN DID SHE SEE HIM LAST -- ALL THE THINGS WE NEED TO DEVELOP AN APPROPRIATE SERVICE PLAN.

BECAUSE OF ADVANCED RHEUMATOID ARTHRITIS, THE WOMAN COULD NOT DO HOUSEWORK, SHOPPING, LAUNDRY, PREPARE A HOT MEAL, OR GET TO HER DOCTOR ALONE. SHE NEEDED HELP BATHING HER BACK, LEGS AND FEET.

THE CASE MANAGER APPROVED SIX HOURS OF HOMEMAKER SERVICE A

WEEK TO CLEAN THE HOUSE, FIX NUTRITIOUS MEALS AND DO THE LAUNDRY AND SHOPPING. TRANSPORTATION FOR DOCTOR'S APPOINTMENTS WAS PROVIDED. HOME DELIVERED MEALS WERE ORDERED FOR THE WEEKEND.

THE NEIGHBOR WHO MADE THE REFERRAL AGREED TO VISIT ON THE DAYS THE HOMEMAKER DID NOT COME. THE CASE MANAGER CONSULTED WITH THE NURSE AT THE HOME CARE CORPORATION AND PERSONAL CARE SERVICES WERE AUTHORIZED TO HELP WITH LIGHT BATHING.

IN ANOTHER INSTANCE, A 74 YEAR OLD WOMAN WAS REFERRED BY A LOCAL HOSPITAL AFTER SHE SUFFERED A SLIGHT STROKE. PRIOR TO ADMISSION, SHE CARED FOR HERSELF AND HER HUSBAND WHO HAD A SEVERE RESPIRATORY CONDITION. THE CASE MANAGER VISITED WHILE SHE WAS HOSPITALIZED TO ASSESS HER FUNCTIONAL LIMITATIONS, THE AMOUNT OF HELP HER HUSBAND COULD PROVIDE, AND THE HOME ENVIRONMENT ITSELF. THE CASE MANAGER MET WITH THE HOSPITAL STAFF TO REVIEW THE POST-HOSPITAL MEDICAL CARE NEEDS, AND THE HOME HEALTH AGENCY TO SEE HOW MUCH AND HOW LONG THEY WOULD PROVIDE CARE.

THE DAY SHE WENT HOME, THE CASE MANAGER HAD ARRANGED TO HAVE A HOMEMAKER AVAILABLE TO FIX MEALS AND CLEAN THE HOUSE.

THE CERTIFIED HOME HEALTH AGENCY PROVIDED A NURSE TO MONITOR NEW MEDICATIONS AND VITAL SIGNS, AND A HOME HEALTH AIDE FOR BATHING, DRESSING AND EXERCISE.

WHEN THE HEALTH CONDITIONS STABILIZED AND MEDICARE BENEFITS RAN OUT, THE CASE MANAGER AND THE HOME CARE NURSE DETERMINED THAT THE CLIENT STILL NEEDED A HOME HEALTH AIDE AND NURSING MONITORING FOR A LONGER PERIOD OF TIME. THE NURSING AND HOME HEALTH AIDE SERVICES WERE AUTHORIZED AND PAID FOR FROM THE STATE FUNDS.

THE ELDER AFFAIRS PROGRAM COVERS A FULL RANGE OF COMMUNITY AND IN-HOME SERVICES. IN ADDITION TO THE SERVICES THESE CLIENTS RECEIVED, WE PROVIDE ADULT SOCIAL DAY CARE, RESPITE CARE, COMPANION, CHORE, AND PROTECTIVE SERVICES.

WE ALSO HAVE A LIMITED $1 MILLION HOME HEALTH PROGRAM FOR PEOPLE WHO ARE NOT ELIGIBLE FOR MEDICAID AND WHOSE SERVICE NEEDS CAN'T BE COVERED BY MEDICARE. THE PROGRAM SERVES ALMOST 600 PEOPLE A MONTH BUT MANY MORE WOULD BE SERVED IF THERE WERE MORE MONEY AVAILABLE.

HOME HEALTH CASES ARE REVIEWED BY THE HOME CARE NURSE AND REFERRED TO CERTIFIED HOME HEALTH AGENCIES FOR SERVICES. THE SERVICE PLAN IS APPROVED BY THE NURSE AT THE HOME CARE CORPORATION BUT THE HOME HEALTH AGENCY STAFF ARE RESPONSIBLE FOR THE CARE PROVIDED IN THE HOME.

OUR DATA SHOWS THAT ELDERS WITH CAREGIVERS ARE TYPICALLY FRAILER, WITH GREATER IMPAIRMENTS IN ACTIVITIES OF DAILY LIVING, THAN CLIENTS WITHOUT A CAREGIVER. CLIENTS WITH A CAREGIVER ALSO

TEND TO USE LESS SERVICE THAN SOMEONE LIVING ALONE. OFTEN THE CAREGIVERS WORK AND THEY NEED ADULT DAY CARE OR SOMEONE TO HELP WITH LUNCH.

OFTEN THE CRUCIAL DIFFERENCE BETWEEN STAYING AT HOME AND GOING TO A NURSING HOME IS A FAMILY MEMBER WHO IS WILLING AND ABLE TO HELP. FAMILY CAREGIVERS ARE A VALUABLE RESOURCE. THEY ARE THE FIRST LINE OF HELP AND THEY MUST BE SUPPORTED. WORKING CAREGIVERS CAN BE SUPPORTED THOROUGH THE REGULAR HOME CARE PROGRAM.

A NEW AND CRITICAL SERVICE FOR FULL TIME CAREGIVERS IS RESPITE CARE. OUR RESPITE PROGRAM PROVIDES UP TO $3,500 A YEAR IN SERVICES THAT ALLOW CAREGIVERS A VACATION, A WEEKEND AWAY OR A FEW HOURS EACH WEEK TO DO ERRANDS OR HAVE TIME TO THEMSELVES. WE WILL SPEND $3.1 MILLION FOR RESPITE CARE THIS YEAR AND WE SERVE AN AVERAGE OF 1200 CLIENTS A MONTH. FAMILIES WITH INCOMES UP TO $44,000 A YEAR ARE ELIGIBLE FOR SERVICES ON A SLIDING FEE BASIS.

CASE MANAGERS USE A SPECIAL MODULE TO ASSESS RESPITE CARE NEEDS. IT IS A COMPONENT OF THE REGULAR NEEDS ASSESSMENT INSTRUMENT USED FOR THIS SERVICE.

EXPANDING NATIONWIDE

MASSACHUSETTS HAS OVER 14 YEARS OF EXPERIENCE WITH CASE MANAGEMENT AND COMMUNITY CARE. A MAJORITY OF THE OTHER STATES HAVE IMPLEMENTED COMPARABLE SYSTEMS AND THE BUILDING BLOCKS ARE THERE IN THE REMAINING STATES. OUR PROGRAM REFLECTS THE PRINCIPLES OF THE LONG TERM CARE POLICY STATEMENT RECENTLY ADOPTED BY THE BOARD OF THE NATIONAL ASSOCIATION OF STATE UNITS ON AGING. I'D LIKE TO SUBMIT A COPY OF THAT STATEMENT FOR THE RECORD.

THE RECENT EMERGENCE OF ORGANIZED COMMUNITY CARE SYSTEMS HAS PARALLELED THE AVAILABILITY OF FUNDING. MANY STATES HAVE BUILT PROGRAMS THROUGH THE MEDICAID HOME AND COMMUNITY BASED SERVICES WAIVER. NEW FUNDING SOURCES QUICKLY PROMOTE NEW SERVICES AND SYSTEMS. PROGRAMS LIMITED TO MEDICAID FUNDING ARE READY TO EXPAND AS NEW FUNDING SOURCES EMERGE.

OVER THE LAST DECADE A WEALTH OF EXPERIENCE HAS BEEN DEVELOPED AMONG THE STATES OPERATING COMMUNITY CARE AND CASE MANAGEMENT SYSTEMS. THE COMBINED EXPERTISE CAN BE ORGANIZED TO HELP THE REMAINING STATES. SPECIALIZED TRAINING AND TECHNICAL ASSISTANCE CENTERS CAN HELP ESTABLISH UNIFORM PROGRAM AND SYSTEM STANDARDS, AND BUILD CAPACITY WHERE IT NEEDS EXPANSION.

TRAINING PROGRAMS FOR CASE MANAGEMENT AGENCIES, PROVIDER

AGENCIES AND STAFF, AND CONSUMERS ARE NEEDED TO ASSURE QUALITY CARE, COST EFFECTIVENESS, AND INFORMED CONSUMER CHOICE.

THE CHALLENGE

WE SEE THREE MAJOR CHALLENGES FOR EXPANDING INDEPENDENT CASE MANAGEMENT AGENCIES:

- WORKER AVAILABILITY
- ESTABLISHING CASE MANAGEMENT STANDARDS
- INTEGRATING CASES MANAGEMENT WITH ESTABLISHED PROVIDERS

THE COMMUNITY CARE SYSTEM SHARES A COMMON CHALLENGE WITH HOSPITALS AND NURSING HOMES -- THE SHORTAGE OF WORKERS TO DELIVER CARE. COMPETITION FOR NURSES, NURSES AIDES, LPNs, HOME HEALTH AIDES AND HOMEMAKERS HAS HAMPERED EVEN THE BEST FUNDED PROGRAMS, PARTICULARLY IN STATES WITH LOW UNEMPLOYMENT RATES.

THE WORK IS DEMANDING. THE PAY IS OFTEN LOWER THAN JOBS IN FAST FOOD RESTAURANTS OR THE RETAIL AND MANUFACTURING SECTORS. BENEFITS NEED TO BE IMPROVED AND THE IMAGE AND VALUE OF THE JOB MUST BE STRENGTHENED. SOCIETY MUST PLACE A HIGHER VALUE ON CARING FOR ITS SICK AND FRAILER MEMBERS.

THE COMMUNITY CARE SYSTEM MUST ALSO ESTABLISH STANDARDS FOR CASE MANAGEMENT SYSTEMS. FOR THESE AGENCIES TO BECOME THE AUTHORIZATION AGENT FOR HEALTH AND SOCIAL SERVICES, TEAMS OF QUALIFIED NURSES AND SOCIAL WORKER/CASE MANAGERS, SKILLED IN

RECOGNIZING FUNCTIONAL, HEALTH AND COGNITIVE IMPAIRMENTS MUST BE RECRUITED. THESE TEAMS WILL FASHION CREATIVE SERVICE PLANS, AND WORK WITH FAMILIES AND COMMUNITY AGENCIES TO COORDINATE CARE.

WE ALSO FACE A CHALLENGE CREATING GOOD WORKING RELATIONSHIPS BETWEEN THE INDEPENDENT CASE MANAGEMENT SYSTEM AND PROVIDER AGENCIES. CASE MANAGEMENT TEAMS WOULD HAVE ARRANGEMENTS WITH CERTIFIED HOME HEALTH AGENCIES TO PROVIDE SKILLED NURSING, HOME HEALTH AIDES, AND THERAPIES. THE CURRENT SYSTEM REQUIRES SEPARATE ASSESSMENTS BY THE HOME HEALTH AGENCY NURSE AFTER REFERRAL FROM THE HOME CARE AGENCY. THE SYSTEM IS SUSCEPTIBLE TO OVERLAP IN THE ASSESSMENT AND SERVICE PLANNING PHASE AND WE NEED TO IMPROVE THIS PROCESS.

THE INDEPENDENT CASE MANAGEMENT AGENCY WOULD BE IN THE BEST POSITION TO DETERMINE WHETHER HOME HEALTH AIDE, PERSONAL CARE, OR PERHAPS AN ADULT DAY HEALTH PROGRAM IS MOST APPROPRIATE AND MOST COST EFFECTIVE. THE AGENCY HAS NO FINANCIAL INCENTIVE TO PREFER ONE SERVICE OVER ANOTHER. STILL, DISTINGUISHING BETWEEN CLIENT SERVICE NEEDS MAY HELP US MINIMIZE OVERLAP.

WE CAN DISTINGUISH BETWEEN THREE TYPES OF CLIENTS AND THE RESPECTIVE ROLES OF THE AGENCIES INVOLVED. THE FIRST CLIENT TYPICALLY NEEDS SPECIFIC HEALTH SERVICES FOR A RELATIVELY SHORT PERIOD OF TIME, BUT LONGER THAN MEDICARE WILL COVER. IN THIS INSTANCE THE CASE MANAGEMENT AGENCY CAN ESTABLISH PROGRAM

ELIGIBILITY AND THE SERVICE PLAN CAN BE IMPLEMENTED BY THE CERTIFIED AGENCY. TYPES OF SERVICE MIGHT BE A MONTHLY NURSE MONITORING VISIT OR INSULIN INJECTIONS.

THE SECOND TYPE OF CLIENT HAS PRIMARILY FUNCTIONAL, RATHER THAN HEALTH NEEDS. A COMBINATION OF PERSONAL CARE, HOMEMAKER, HOME DELIVERED MEALS AND TRANSPORTATION MAY BE EFFECTIVE. NO INVOLVEMENT WITH THE CERTIFIED AGENCY IS NEEDED AND THE CASE MANAGEMENT AGENCY ARRANGES THE NECESSARY SERVICES.

THE THIRD TYPE OF CLIENT HAS MORE COMPLEX NEEDS. THE CLIENT HAS A MIX OF HEALTH AND FUNCTIONAL NEEDS. SERVICES MAY BE SUBSTITUTED. THE INDEPENDENT CASE MANAGEMENT AGENCY NEEDS TO COMPLETE BOTH ELIGIBILITY ASSESSMENT AND THE SERVICE ASSESSMENT. BASED ON THE SERVICE ASSESSMENT, THE CASE MANAGEMENT AGENCY CAN DETERMINE WHETHER A HOME HEALTH AIDE, PERSONAL CARE WORKER OR A DAY HEALTH PROGRAM IS MOST APPROPRIATE.

THESE ASSESSMENTS AND DECISIONS ARE BEST MADE BY AN INDEPENDENT AGENCY BASED ON THE NEEDS OF THE CLIENT, THE COSTS OF CARE AND THE AVAILABILITY OF SERVICES IN THE COMMUNITY.

THESE ARE THE CHALLENGES THAT COMMUNITY CARE PROGRAMS AROUND THE COUNTRY MUST RESOLVE. THEIR RESOLUTION WILL BE CRITICAL TO THE COST EFFECTIVENESS AND THE QUALITY OF CARE PROVIDED TO OUR

FRAIL ELDERS. AS WE MOVE AHEAD, I AM CONFIDENT THAT WE HAVE THE KNOWLEDGE, THE EXPERIENCE AND THE CAPACITY TO IMPLEMENT A NATIONAL LONG TERM CARE SYSTEM THAT PROMOTES INDEPENDENCE, MAINTAINS ELDERS IN THE COMMUNITY, RECOGNIZES THE NEED AND IMPORTANCE OF NURSING HOME CARE, AND AT LAST -- LIFTS THE BURDEN FOR PAYING FOR LONG TERM CARE FROM FAMILIES AND SPOUSES. UNIFORM ACCESS TO AFFORDABLE CARE IS WITHIN OUR REACH.

TO A LARGE EXTENT, STATES HAVE BEEN THE LABORATORIES FOR LONG TERM CARE -- DEVELOPING MODELS FOR PROVIDING SERVICES, ASSESSING AND SERVING FRAIL ELDERS, FINANCING CARE, AND ADMINISTERING CASE MANAGEMENT SYSTEMS. WE KNOW HOW TO DO IT. WHAT WE NEED IS A UNIFORM NATIONAL POLICY DESIGNED TO MAINTAIN ELDERS IN THE COMMUNITY, TO SUPPORT FAMILIES CARING FOR FRAIL ELDERS, AND TO HELP PAY FOR CARE IN A NURSING HOME WHEN IT IS NECESSARY.

THANK YOU.

FEDERAL LONG TERM CARE REFORM:

A PROPOSAL

BY THE

NATIONAL ASSOCIATION OF STATE UNITS ON AGING

Adopted

June 10, 1988

NASUA Membership Meeting

FEDERAL LONG TERM CARE REFORM:
A PROPOSAL BY THE NATIONAL ASSOCIATION OF STATE UNITS ON AGING

The issue of long term care is currently the subject of considerable debate at the national level. Several options for improving the financing of long term care have been proposed, ranging from modest attempts to encourage private financing mechanisms to full federal coverage of all long term care. As architects and administrators of state community based long term care programs for the elderly, the NASUA membership is uniquely able to propose new federal initiatives by drawing upon their experiences in developing the community care systems already in place.

One of the major problems confronting persons needing long term care is the institutional bias in the current system. Because of the lack of meaningful federal funding for home care, nursing homes are currently the principle providers of long term care for persons who do not have spouses or other family members able to provide all the necessary assistance. Nursing home costs are a devastating expense to families. Medicaid requires impoverishment of its beneficiaries. In addition, Medicaid nursing home costs are driving state budgets into a squeeze which will affect quality of care.

States that have undertaken efforts to create home and community based long term care services know that individuals with serious disabilities can be served in a variety of settings. State community care systems are meeting individual long term care needs at lower costs than nursing homes, with a high level of consumer satisfaction. Unfortunately, it is too difficult to use federal financial participation under Medicaid to meet all the demand for community care, and far too many elderly are barred by means testing from using these programs.

This paper outlines a proposal for federal long term care legislation that would build on the systems in which most states already have a major investment. The proposal uses as its beginning point the principles adopted by the Board of Directors of the National Association of State Units on Aging (NASUA), including:

- In the face of the rapidly growing population of older people, especially the very old, a federal social insurance program must be the basis of long term care financing.

- The program should provide universal benefits for older persons, with a predictable, uniform long term care benefit.

- Those receiving benefits should participate in the costs of long term care services, based on their relative ability to pay.
- Administration of the program should be primarily the responsibility of states, the governmental level with the most experience in this area.
- Day-to-day management of benefits should be locally based, so differences in local service delivery systems are recognized.
- The first federal dollar of the new program should be for home and community care, to overcome the bias in current federal financing mechanisms toward institutional care.
- Covered services, regulations and standards should be family-oriented and biased toward the least intrusive home and community based assistance.
- Eligibility for receipt of benefits should be based on functional capacity, not medical diagnosis or physician prescription.
- Quality assurance mechanisms should be based on an individualized, case managed system.

Within this broad framework of policy principles, we propose a comprehensive package of federal legislation creating new benefits for long term care within a new Medicare Part C, building upon an accepted and well known program and financed through a variety of funding mechanisms. This will provide universal coverage for all Medicare enrollees. The operation of the new long term care benefit must, however, be fundamentally different from that of the current Medicare program if efficiency, cost-effectiveness and consumer satisfaction are to be assured in the delivery of these primarily non-medical services. The balance of this paper describes the components and operation of the program we propose.

PROGRAM PARTICIPANTS

NASUA's proposal addresses the long term care needs of persons eligible for Medicare coverage (persons age 65 and older and certain disabled adults). We recognize that persons of all ages and disabilities may need long term care services. In fact some state programs currently serve multiple populations and there is considerable overlap among groups -- some persons with disabilities are also older. Our expertise and program experiences, however, make us best qualified to propose program components designed for the elderly.

Therefore, while NASUA supports efforts to reform long term care services and systems that also serve younger disabled persons, this proposal focuses on services for older persons.

The full range of benefits should be universally available to all Medicare participants based on functional, not financial need. The requirement for impoverishment that is currently part of the Medicaid long term care benefit should be avoided in the new program. Any consumer cost-sharing mechanisms should be modest, with persons who are least able to pay exempted from incurring these out of pocket expenses.

BENEFIT DETERMINATION

Functional status should be the primary criterion for determining eligibility for program benefits. A comprehensive assessment shall measure a person's ability to consistently and appropriately perform essential activities of daily living (bathing, dressing, toileting, eating, transferring) based on the person's physical, cognitive and emotional/behavioral functioning and shall review health conditions that may require in-home services. An assessment finding that the person's functional disability results in the need for human assistance in performing two of the five specified activities of daily living will result in eligibility for program benefits.

The need for nursing care should be reviewed as part of the assessment process; however, service eligibility will not be dependent upon a need for health services. State experience indicates that some persons in need of long term care have limitations in performing activities of daily living and yet do not need health services. In addition, eligibility should be established without regard to the underlying condition or medical diagnosis resulting in disability; specific types of conditions which may result in impairments (e.g., developmental disability, chronic mental illness, chemical dependency) should not be excluded.

Client functional assessments will be performed by state designated case management agencies and will include a face to face interview with the individual and his or her caregiver. Standards for functional eligibility should be federally defined and uniform across states. The Secretary of DHHS, in consultation with states, will develop the protocol for determining eligibility, including the components of the assessment tool used to measure impairment levels.

States will be required to establish a process for timely resolution of appeals resulting from denial of service eligibility. In those instances where a state has upheld the initial decision of a case management agency, individuals will have the right of appeal to the federal government.

The development of written individual care plans will be based on the findings of the assessment process. In addition to measuring functional capacity for determining program eligibility, the assessment should gather current, valid and comprehensive information about the individual's health condition and her/his home and community environment to determine what services, supports or other environmental modifications would assist the person to live and participate in families and communities. States shall develop, with federal approval, the components of the assessment tool used to identify the services needed to meet the unique needs of individuals with varying disabilities, service preferences and living arrangements. This determination will be made within the context of local service delivery systems and an available local work force, both of which will vary across the country. In addition, an assessment of the adequacy of the individual's informal support system (currently existing and in the near future) will identify the more personal and informal care that family and friends are willing and able to provide and that the consumer has agreed to accept. At the same time, within the context of an entitlement program, the eligibility criteria will not require any level of assistance from families or others. While this program should build upon the informal care system already in place, older consumers should not be penalized if families are unable to provide assistance.

The state designated case management agency will develop individual care plans, specifying in some detail the type and amount of needed services. Only through the development of care plans by the case management agency will specific program benefits be authorized for individual consumers. Attending physicians and other health care professionals involved with individual consumers should be consulted during the care planning process when appropriate, but will not be required to approve those portions of care plans which primarily utilize non-medical support services.

The case management agency must take into consideration the preferences of individual consumers in designing care plans. To assure consumer acceptance, the individual (and the informal caregiver in instances where a substantial amount of care is to be provided by a family member or friend) should have final approval of the care plan. States shall be required to establish a process for timely resolution of grievances and appeals related to the decisions of the case management agency.

All case management functions, including assessment and care planning, shall be performed by an entity which is not a service provider to reduce the potential for conflict of interest. If necessary, this requirement could be waived during an initial start-up period to allow new service delivery systems to be created. Governmental agencies should also be exempt from this requirement, provided that two distinct organizational units provide case management and direct services. In addition, exemptions should be allowed for state designation of entities which accept financial risk for all long term care needs of their enrollees, and which are voluntarily chosen by beneficiaries. These entities will agree to have eligibility determination for their enrollees performed by an independent entity and will submit to ongoing oversight of their case management and service activites.

BENEFIT PACKAGES

NASUA's legislative proposal includes both a home and community based care benefit and a limited nursing home benefit.

Ideally, the specific home care services that could be supported through this new program would not be delineated in federal law, but would rather be individually tailored to respond to the needs of an older person as identified through the assessment process. A major shortcoming of the Medicare and Medicaid programs as currently designed is the lack of flexibility in the types of home care services that can be provided; available services therefore correspond to federal rules rather than to the unique needs of individuals. Under this new program, case management agencies should be able to authorize the provision of any service that assists an older person to carry out activities of daily living, maintain social integration and family supports, enhance consumer self direction, and prevent inappropriate institutionalization.

Our reluctance to delineate a specific package of allowable services grows out of three concerns: 1) This program should avoid the design mistakes of Medicare and Medicaid and encourage the development of creative responses to individual needs rather than fitting the needs of older people into rigid service categories. 2) Certain services can substitute for another, depending upon client needs and preferences and the availability of home care staff. For example, assistance in meal preparation can be addressed through personal care services, a live-in personal care attendant or home delivered meals. 3) The assistance typically needed by older persons to cope with activities of daily living are supportive services rather than medically oriented services, and such services are best described as a response to individually assessed needs. Our experiences with similar programs indicate that specifying a set of allowable services has frequently resulted in a medical model, and in turn in a service response that is less flexible and more expensive than necessary.

States should be required to assure that a broad range of services are available to enhance the independent functioning of program beneficiaries. In addition, community based long term care services should be provided in a variety of settings, including in a person's own home (on either a visiting or live-in basis); in congregate service centers such as adult day care centers that provide therapeutic programs and socialization opportunities; and in alternative living arrangements such as foster homes, board and care facilities and shared housing. However, room and board costs in community settings would not be covered by this program. To illustrate the potential array of services, the following set of services should be included within legislation as examples of allowable services: personal care, chore, adult day care, respite care, personal supervision, nursing, therapies, home health care, transportation to and from service centers, assistive devices, home and financial management, and minor home or vehicle modifications. It will be crucial to assure that the current Medicare acute benefits of skilled home nursing, therapy and home health aide services be in no way diminished.

Within the constraints of cost limits, local service supply and quality assurance, consumers (or their guardians if the individual has been adjudicated incompetent) will be able to chose the **type** of living arrangements they will have while receiving services (e.g., whether to live in group settings) and the **types** of services to be provided (e.g., whether a need for assistance with meal preparation will be met through home delivered meals or a homemaker). Again, the same services can be provided in a variety of ways. Consumers' preferences must be honored to the greatest extent possible in choosing the specific provider of services, within the limits of cost-effectiveness and quality assurance. For example, consumers should not be able to choose a provider that does not meet program standards, that has service unit costs that are significantly higher than other providers of identical services, or that is not available in the individual's community.

States should not be precluded from including individuals (not affiliated with agencies) as formal providers, so long as the individual meets federal, state or local training or other requirements and is approved by the case management agency. Such client employed provider arrangements can potentially offer consumers substantial control over the implementation of their care plans.

In order to control overall program costs, an annual limit on the per person benefit should be established for home care and tied to 75 percent of the average Medicare rate for skilled nursing facility care in the state. This provision also ties increases in the cost limit for the per person home care benefit package to increases in the average Medicare rate for skilled nursing facilities.

Several explicit exclusions from the payment cap will be important. First, acute care benefits received during an episode of illness and currently covered under Medicare should be excluded. Second, the costs of assessments, care planning, ongoing case management and service monitoring should not be included. Case management is an important process for utilization control, cost-containment and quality assurance, but should not be applied to the limit on personal services. Instead, case management costs should be reimbursed on a capitated cost per client, with such rates varied to reflect differences in local wages while responding to federal expectations about minimum client and provider contact, as well as maximum reasonable average time spent per client.

NASUA believes that the primary emphasis of any new federally financed long term care program should be on expanding the availability of home and community based care. Consumers overwhelmingly prefer to remain in their own homes and communities to receive needed care. A number of states have proven that community care can be provided for consumers needing the same level of care as those who enter nursing homes and that on average, it is less expensive to do so. Yet the ease of arranging for all needed care through placement in a nursing home creates incentives for families and care managers (hospital discharge planners, physicians, etc.) to opt for nursing home care instead of packaging community based arrangements. At the same time, we recognize that at some point in their lives, older people may have needs that can only be met through nursing home care.

In many parts of the country, the long term care system is significantly out of balance, with institutional capacity and expenditures far outstripping those on the home and community side. A major new federal entitlement to long term nursing home care, absent the current utilization disincentives resulting from Medicaid income and asset limits, would result in a rapid growth in nursing homes and related costs.

Reflecting these concerns, NASUA proposes that the benefit package cover nursing home care beginning with the day of admission and be limited to 100 days in a given calendar year for all admissions. Consumers will make no co-payment for the first 20 days and a 20 percent co-payment for the remaining 80 days. Medicaid would cover the consumer share for eligible persons. This short term coverage is designed to encourage active discharge planning beginning at the time of admission and help preserve consumer resources so that return to the community is feasible following a short term nursing home stay. The case management agency will authorize access to both the nursing home benefit and the home and community care benefit.

The proposed benefit replaces the current Medicare nursing home benefit, covers either SNF or ICF care, assumes implementation of the spousal impoverishment provisions of the Medicare Catastrophic Coverage Act, and allows for a potential role for private long term care insurance. In addition this benefit recognizes that over one half of all nursing home stays are for less than 100 days.

PROGRAM MANAGEMENT

States must play a strong role in the administration of this new benefit program. By assigning states management responsibility, this new program will build upon the long term care systems development work already underway, significantly reduce start-up costs, and enhance integration with existing programs. Within broad federal parameters, states will:

- designate and certify case management agencies;
- define standards for care plan development;
- assure availability of a full array of home and community based services;
- develop or direct the local development of contracts with qualified providers to participate in the program;
- define allowable provider costs;
- develop provider reimbursement systems; and
- monitor quality and train providers.

These responsibilities can be exercised within a framework of federal regulations, while at the same time reflecting the experience and expectations of state and local officials and consumers themselves. Administrative costs of the state shall be covered primarily by federal financing with some state financial participation.

Fiscal intermediaries would have a role only to the extent that states choose to contract for purely administrative functions. Fiscal intermediaries would not be empowered to second-guess decisions of case managers, as they do with current Medicare providers. Rather, their role would be to perform the mechanical tasks of billings and claims processing and to produce whatever data reports are contracted for by the state to meet state or federal requirements.

State certified case management agencies will conduct individual functional assessments, certify consumer eligibility for benefits, develop care plans specifying the amount, type and duration of program benefits, authorize the delivery of services and monitor, on an ongoing basis, the implementation of care plans. Case managers will be paid for these activities on a capitated basis. Case management agencies may contract directly with service providers to the extent authorized by the state.

QUALITY ASSURANCE

States should be required to develop mechanisms to assure the provision of quality care for both home and community based care and nursing home care. Standards for nursing home care are incorporated in the Nursing Home Reform Act of 1987. Standards for most home and community based services should not reflect typical medical model criteria (such as professional provider credentials) that are likely to increase costs unnecessarily. Instead quality assurance mechanisms should focus on achieving maximum consumer functioning and reflect consumer preferences. By using a managed care approach, case managers will, on an ongoing basis, monitor the implementation of individual care plans to make sure that beneficiaries receive assistance appropriate to their needs and preferences. In addition states must assure that:

- Assessments and care plans are completed and service delivery initiated within a reasonable time period after consumer contact with the case management agency.
- An appeal mechanism exists to consider grievances on eligibility determination, amount, type and duration of services authorized in care plans, and the manner in which services are provided.
- Providers comply with requirements for state certification and with relevant employment laws including those related to minimum wage and payment into social security and unemployment compensation funds.
- Providers have a demonstrated capacity to deliver services.
- A mechanism will be established to receive and investigate complaints.
- A state advisory committee whose membership reflects a balance of consumers and other interested parties will be established to provide input on all aspects of program design, with particular emphasis on mechanisms to assure quality care.

The federal government will also establish sanctions to be taken against states found to be out of compliance with minimum program standards and will assist states in enforcing sanctions against local case management agencies or direct service providers.

FINANCING

Funds to support this program will be generated by three major sources: beneficiary premiums, consumer co-payments and revenues generated through the Medicare payroll tax (primarily raised by lifting the $45,000 ceiling on

The **Chairman**. Dr. Weissert.

Dr. **Weissert**. Thank you, Senator Kennedy.

I am here to talk as a health services researcher. I have spent the last 15 years of my career working mainly on the subject of the cost effectiveness of home health care, beginning with the study of adult day care in the mid-1970's, and more recently with a study of cost management that I am doing for the Pew Charitable Trusts. I have also recently summarized the results of the 24 demonstration projects that have been funded by Congress in home and community care.

What we find in those demonstration projects is that home care really does have an effect on people's lives. If it does nothing else, it raises life satisfaction of both the patient and the family caregiver.

There was a hope for a long time that it would save money; that has been, I think, disproven in large part because it was kind of a silly idea that you could expand care to this really needy population and expect that to produce substantial savings.

My research shows that with careful design of the benefit, however, you can make home care something we can afford, even in tight money times like this. I think this piece of legislation has done a brilliant job of doing that: making it an affordable package which greatly enhances its chances of passage. And I think that is probably the most terrific contribution it makes in that sense.

It builds on the research that we have done in this field. It offers a broader array of services than most other bills. The important thing it does is to tie the level of the benefit to the intensity of the patient's need. And it bases that need on risk of institutionalization, dependency in activities of daily living, and the need for social support.

The important thing is it would give the most services to the most dependent people. It also leaves substantial discretion in the hands of the State agency, which is important in this area, and it provides funds for training, research, and care planning, which is an area that we desperately need some more help in.

Let me comment just briefly on the nursing home section of the bill.

The problem is that even short stays in nursing homes are catastrophic. A 6-month stay is a $12,000 expenditure, and that's the stay that most people have. Two-thirds of stays are 6 months or less, and so most people experience a short stay.

People think Medicare covers it, but it doesn't. What this bill would do is assure that no one is going to be denied access or delayed access to a nursing home because they don't have the money to pay for it, and that would be a major change in the way things currently operate where nursing homes typically prefer people who can pay their own way.

The bill gives everybody six months' coverage under Part A, with no attached extra premiums——

The **Chairman**. Dr. Weissert, excuse me. As you can tell, we have another vote. I'd like to hear, if I could, Mr. Lifson for a few minutes, and then if you'd be kind enough, I have some technical questions, and I am going to ask my counsel to keep you here and get into that, if you would. But I want to give everyone an opportunity to be heard, and again, I apologize to all of you.

[The prepared statement of Dr. Weissert follows:]

Testimony on
Senator Edward M. Kennedy's Lifecare Insurance Program

Presented to the Committee on
Labor and Human Resources
United States Senate

by

William G. Weissert, Ph.D.
Professor of Health Policy and Administration and
Director, Program on Aging
School of Public Health
The University of North Carolina at Chapel Hill

August 3, 1988

Senator Kennedy and members of the Committee, thank you for the opportunity to appear before you to urge that the Congress support this important and historic piece of legislation which would eliminate the burden of catastrophic nursing home costs and extend basic home care to that relatively small number of very sick physically and mentally dependent elderly Americans and their families who are currently left out of the health care financing system: those who live in the community and need human help to bath, dress, toilet, maintain continence, move from their beds and chairs, and eat.

The need for home care by approximately two million elderly individuals and their families has been eloquently demonstrated by the speakers who have appeared before me. My contribution is to speak from the less passionate but no less concerned perspective of the health services researcher. I have had the privilege for the past 15 years of devoting the majority of my research efforts to the study of the costs and effectiveness of home and community care for the dependent elderly. Beginning with a study of adult day care and homemaker services in the mid-1970's undertaken on behalf of the National Center for Health Services Research (an agency of the federal government which owes its existence to this committee and its counterparts in the House of Representatives), and most recently with a study of home care cost management funded by the Pew Charitable trusts, I have conducted research on all aspects of home care for the elderly and have recently synthesized my own and others' findings from more than two dozen home care experiments which my colleagues and I have undertaken over the past three decades. Results show that those who receive home care as well as their caregivers, experience improved life satisfaction. A fantasy that such needy populations could be provided this care as a money-saving strategy has now largely been laid to rest, but my research supports the conclusion that with careful design of the benefit along the lines suggested by this legislation, home care for the dependent elderly is affordable even in tight money times.

This bill builds upon that considerable body of home care research. In addition to offering a broader array of services than other bills, it ties the amount that can be spent on an individual to his or her need as measured by dependency and the availability of social support. It would assure that the most dependent persons were provided the most services. By tying entitlement to the likelihood that the individual would be institutionalized without home care, the bill would assure that home care costs could not go out of control. In contrast, the flat entitlement in some other bills would authorize the same spending for someone dependent only in bathing or dressing as it would for someone dependent in all six activities of daily living. Flat entitlement would invite cost inflation by those serving the less dependent while encouraging denial of care to those who are most dependent.

The need for research to produce improved algorithims for authorizing and planning home care is clear from the many studies which show enormous variability in utilization and costs. The bill wisely authorizes such research and also provides for training of case managers to better equip them to write good care plans. Leaving discretion in the hands of the care authorizing agency to balance the entitlements of more and less needy recipients is a brilliant stroke in this bill because it acknowledges that while aggregate data are adequate for estimating the care needs of groups, actual care planning must be left in the hands of clinicians working with the patient and family. While there is no doubt that improvements and adjustments will be made in specific details of the bill's home care portion as it goes through the legislative process, it is a testament to you and your staff that you have offered such a thoughtful and technically appropriate approach to this complex issue.

Let me speak now briefly in favor of the second major section of the bill - coverage of nursing home care. Again, the need for protection from the catastrophic losses which result from nursing home use - even short term nursing home use - has been clear for many years. Sadly, most people think Medicare already provides such coverage, but of course it does not. While current law technically authorizes 100 days of nursing home care, restrictions on the level and type of care limit actual coverage to less than 30 days on average, and to only a very small fraction of those who need care. Elderly Americans deserve to be assured that if they need nursing home care, there will be money available to pay for it.

This bill would assure that no one is denied care for lack of funds. But its approach is bold and sensible. Even under the catch-as-catch-can financing system we now have, more than one fourth of admissions go back home from the nursing home. Presumably these are individuals who had enough money so that they still had a home to go to even after paying their nursing home bill. With adequate financial coverage of short nursing home stays, more people might be able to go back home after a relatively short stay. This bill would provide such coverage as a Part A benefit for up to 6 months stay. A study which I recently conducted in North Carolina shows that this provision would wipe out much of the problem of elderly people stuck in hospitals because no nursing home wants them until their Medicaid financial eligibility has been proven - a process which takes several weeks.

Long stay nursing home residents are quite a different matter, however. Research shows that chances of going home after a 6-month stay are extremely limited. People who experience stays of more than 6 months are most likely to die in the nursing home or be transferred from the nursing home to a hospital and die there.

Without insurance coverage, a person's life savings can be wiped out by nursing home charges. Long-term care insurance can provide protection so that this won't happen, but who should pay the premiums? For long-stayers, the money they are spending for nursing home charges would otherwise become their estate. While there are many good reasons why elderly Americans want to protect their estates and pass them on as inheritance to their adult children and grandchildren, it seems reasonable that the potential estates can afford to pay the premiums. That is why the bill treats long-stay coverage as an optional Part B benefit financed by beneficiary premiums. And by covering the first 6 months as a Part A benefit, costs of long stay insurance can be kept affordable.

No other piece of legislation ever introduced into this Congress or, to my knowledge, to any state legislature has heretofore recognized this simple fact: Most nursing home stays are short. People need protection from short stay costs which can seriously impair their ability to return to the community. But when stays extend beyond six months, they are likely to result in death in the nursing home or another health care facility. Coverage of short and long stays should be treated differently. Society has a profound interest in helping potential short-stay nursing home patients get back to the community. It has a significantly less important interest in assuring that long-stay patients keep their estates intact for passing on to their heirs.

The Kennedy bill makes this appropriate distinction. Society would guarantee coverage of all short stays under Medicare, it would offer affordable insurance to those with estates to protect themselves against long stays, and it would rely on the existing Medicaid program to provide long-stay coverage for those whose estates are too small to warrant insurance coverage and whose Social Security and pension payments are not enough to cover their monthly nursing home charges.

In my opinion, based upon my own considerable research in nursing home financing and reimbursement and my familiarity with the findings of many others, this is one of the most enlightened pieces of legislation ever to be introduced on the subject of long-term care financing. For a researcher who often finds himself trying to see any discernible link between health services research findings and the legislative process, it is a rare privilege indeed to speak on behalf of a piece of legislation which is so obviously based upon relevant research.

Thank you very much for this opportunity to speak in its support.

Mr. **Lifson**. Thank you very much, Senator Kennedy.

I am Arthur Lifson, Vice President of EQUICOR, Inc., and I am representing the Health Insurance Association of America, which has some 350 insurance companies as its members, who write over 85 percent of all commercial insurance.

The industry is justifiably proud of the role it has played in the evolution of the largest private insurance system in the world. The situation did not occur overnight. It evolved mainly after World War II, as the Nation's growth and productivity increased national income and allowed people to look beyond cash income to securing themselves against premature death, unexpected illness, or disability and planning for retirement.

We are now entering the next logical phase of this evolution. The advances in both medical technology and general health that are increasing the lifespan of the elderly are also increasing the number of people who may require treatment for chronic illness. Simultaneously, rising income, particularly among the elderly, makes insurance against the cost of long-term care both desirable and affordable. The time has come to begin folding long-term care into the country's extensive private insurance system.

Long-term care is the major catastrophic health care expense faced by today's elderly. On average, for those elderly with out-of-pocket health care expenses over $2,000 a year, 80 percent goes toward nursing home care. The public and private sectors are just beginning to focus on the need to establish a systematic program of insuring long-term care costs.

There has been very little pre-funding of private resources to minimize the financial drain of long-term care. As a result, as we heard from the panel before, many middle-income individuals must spend down to become eligible for Medicaid.

Long-term care embodies many of the characteristics of a situation suited to insurance, potentially a very expensive event, difficult to predict for a given individual, and for which the frequency is sufficiently low that cost per person spread across a large group can be relatively modest.

The HIAA recognizes that private insurance cannot provide the answer for everyone. Providing care for individuals with low incomes should be the objective of public programs, and reforms are needed to improve the Government's ability to act upon their behalf.

For those individuals who can be expected to protect themselves, the market for long-term care insurance has changed dramatically. There are now about 80 companies selling long-term care products—almost all this growth since 1985. There are more than half a million policyholders, and some companies report doubling the number of policies in force each year.

More importantly, the products themselves are changing rapidly. Virtually all the new products offer nursing home and home health care, frequently without prior hospitalization. Benefits are triggered based upon functional limitation measures. In addition, some policies have inflation protection.

The recent introduction of employer-sponsored plans is particularly promising. Such plans offer the opportunity to efficiently reach a large number of people during their working years when premiums are affordable. The enrollment experience in employer plans has shown that the average age of employees electing the coverage is the early forties. This is strong evidence that, with education, younger people can and will purchase long-term care protection. Most of these plans also provide coverage to the elderly, including retired employees and parents of workers and workers' spouses.

As you know, there have been other hearings before other committees on tax matters, and I will skip over that.

In the national debate over the multitude of worthwhile activities to which our scarce resources can be put, the HIAA questions whether any proposal to use tax dollars for those Americans who can finance their own long-term care is the best way to solve the Nation's long-term care financing problem. Given Medicare's current commitment and future promises, the cost of this new proposal must be weighed against the need for additional revenue to assure Medicare's existence.

The Part A Trust Fund remains financially unstable. When it goes broke, it stays broke. Part B premiums have risen dramatically in recent years and will continue to do so unless there is strong action taken.

The new catastrophic legislation adds to the need to raise future premiums and taxes.

In designing the structure of the future public and private sector financing arrangements, HIAA believes that more analysis needs to be done to determine the most effective model through shared responsibility and to determine the most fiscally-responsible system over the long run. We need to explore more ways to achieve this balance before settling prematurely on any untested concept.

The CHAIRMAN. I am going to have to leave.

Mr. LIFSON. Thank you.

[The prepared statement of Mr. Lifson follows:]

Statement
# of the
Health Insurance Association of America

On

LONG TERM CARE

Presented by

Arthur Lifson

Vice President, Government Relations

Equicor, Inc.

Before the

Committee on Labor

and Human Resources,

U.S. Senate

August 3, 1988

Good morning Mr. Chairman and Members of the Committee. I am Arthur Lifson, Vice President of Equicor, Inc.

Today, I also represent the Health Insurance Association of America. The HIAA represents some 350 insurance companies which write over 85 percent of all commercial health insurance in this country.

The insurance industry is justifiably proud of the role it has played in the evolution of the largest private insurance system in the world. The overwhelming majority of adult Americans now have private life and health insurance and the great majority also participate in pension plans.

This situation didn't occur overnight. It evolved, mainly after World War II, as the nation's growth and productivity increased national income and allowed people to look beyond cash income to securing themselves against premature death, unexpected illness or disability, and planning for retirement.

Now, we are entering the next logical phase of this evolution. The advances in both medical technology and general health that are increasing the lifespan of the elderly are also increasing the number of people who may require treatment for chronic illness. Simultaneously, rising income, particularly among the elderly, makes insurance against the costs of long term care both desirable and affordable. The time has come to begin folding long term care into this country's extensive private insurance system.

My testimony will focus on three areas:

- the nature of the long term care problem and why it lends itself to insurance coverage;
- the new developments in long term care insurance products;
- the challenges we face in attempting to meet the need for long term care insurance.

Nature of the Problem

When we speak of "long term care", we are describing a wide range of medical and support services provided to individuals who have lost some or all capacity to function on their own due to a chronic illness or condition and who are expected to require these services for an extended period of time. About 70 percent of the noninstitutionalized elderly with long term care needs receive their help solely from family members and friends. However, others need paid home care services and nursing home care.

Long term care is the major catastrophic health care expense faced by the elderly today. On average, for those elderly with out-of-pocket health care expenses over $2,000 a year, 80 percent goes toward nursing home care. With nursing home costs estimated to average $22,000 - 25,000 per year, such expenses can indeed cause financial ruin.

Over the last three decades, both the public and private sectors have focused their attention on the enormous tasks of improving the scope of coverage for acute health care and the financing of pension plans. The public and private sectors are just beginning to focus on the need to establish a systematic program of insuring long term care costs. Currently, nearly half of all nursing home costs is paid for by Medicaid and the other half is financed out-of-pocket on a pay-as-you-go basis. There has been very little prefunding of private resources to minimize this financial drain. As a result, middle income people are forced to impoverish themselves, "spending down" almost all of their resources and becoming eligible for Medicaid -- a health care program intended for the poor. This all-or-none financing approach also encourages some people to divest themselves of assets in order to qualify for Medicaid benefits.

Not everyone will need paid long term care services. For example, it is likely that somewhere between 60 and 75 percent of the elderly will never enter a nursing home. Of those that do, about half will be institutionalized for more than 90 days. Therefore, long term care embodies many of the characteristics of a situation suited to insurance: a potentially very expensive event, difficult to predict for a given individual, and for which the frequency is sufficiently low that the cost per person, spread across a large group, can be relatively modest.

Private insurance, however, cannot provide the answer for everyone. Insurance products are not designed as financing vehicles for some segments of the population such as those with low incomes. Providing care for this population should be the objective of public programs and reforms are needed to improve the government's ability to act for those who must rely upon it.

New Developments in Long Term Care Insurance

There has been a small private market for long term care insurance in this country for some time. However, widespread consumer misunderstanding about the extent of Medicare coverage, coupled with other, higher priority uses for their funds were two of the primary reasons why spending for private long term care insurance has had little appeal.

Recently, that has changed dramatically, as evidenced by the number of companies developing long term care insurance products, the number of individuals covered and the variety of products being developed. There are now about 80 companies selling a long term care product and almost all of this growth is since 1985. Today, there are about one-half million policyholders. Some companies report doubling their number of policies in force each year.

More importantly, the products themselves are changing rapidly. Because of the lack of experience, the early products tended to be more limited. For instance, they covered only stays in a nursing home and then only following a hospital stay. But virtually all of the newer products offer nursing home and home health care, frequently without a prior hospitalization. Instead, benefits are triggered based on functional limitation measures. In addition, some policies are now providing inflation protection against future long term care costs. We will see a continued trend toward more comprehensive and liberal benefit provisions as private sector insurers and the consuming public become more sophisticated.

The recent introduction of employer-sponsored plans is particularly promising. Such plans offer the opportunity to efficiently reach a large number of people during their working years when premiums are more affordable. A year ago when the HIAA testified before the Senate Finance, Subcommittee on Health, only one employer plan had been introduced. Six months later, at the end of 1987, there were five more. Several employers have expressed interest in offering a plan in 1988.

The enrollment experience to date has shown the average age of the employees electing this coverage is in their early 40's. This is strong evidence that with education, younger people can and will purchase long term care protection. And, most of these plans provide coverage to the elderly including retired employees and parents of the worker and worker's spouse.

The insurance industry is moving rapidly to serve more people and offer a wider range of services. Clearly, the availability of home and community-based care are highly desirable from a social perspective and can also be cost-effective under the appropriate conditions.

Challenges to the Long Term Care Insurance Market

There are several factors which have inhibited the development of long term care insurance. In varying degrees, these factors still operate today. The most important of which are:

- A low level of consumer awareness about the risks and costs of long term care, coupled with a widespread belief that Medicare and supplemental Medigap policies cover long term care costs.

- A lack of usable data by insurers regarding the use and costs of long term care services, particularly in an insured environment, which makes actuarially sound pricing of products difficult.
- An uncertain public sector tax and regulatory environment for companies developing long term care insurance.

Consumer Awareness

The need for better consumer education is the responsibility of both the private and public sectors. It should begin early, so that people can purchase insurance when they are younger and premiums are more affordable.

HIAA has undertaken a number of initiatives in this area. I would like to submit for the record one example of our efforts, the Consumer Guide to Long Term Care Insurance. HIAA remains willing to work with all levels of government to further these communication and education efforts.

Data Needs

The development of an effective plan design and the appropriate pricing of policies relies on a good body of data. The data that do exist are fragmented and in many areas are lacking. For example, there are almost no data on the rate at which private pay patients exhaust their resources to become Medicaid eligible. And, information on the lifetime use of nursing home care is also limited.

Our knowledge gaps make it very difficult to predict the future costs of any long term care program, whether publicly or privately funded. Furthermore, these uncertainties strongly suggest that the private and public sectors move incrementally in order to create a sound national policy.

Federal Tax Environment

Long term care insurance is a new product which has an uncertain status under the current federal tax code. In order to stimulate the growth of private insurance, especially employer sponsored coverage, and to reduce the costs of long term care insurance, it is necessary for the federal government to clarify the tax status of long term care insurance and to remove barriers to several logical and effective product designs.

State Regulatory Environment

Long term care insurance is a new product that continues to evolve. Insurers need a state regulatory environment which is sufficiently flexible to allow for the development of new and different products but is equally effective in protecting consumers. In December 1986, the National Association of Insurance Commissioners (NAIC) adopted model legislation that successfully balances these two objectives. In the last 18 months, 13 states have passed the model bill and another 8 are expected to pass this bill by the end of 1988. HIAA supports this critical legislation and is working actively in those remaining states for its passage.

Finally, HIAA questions whether any proposal to use tax dollars for those Americans who can finance their own long term care is the best way to solve the nation's long term care financing problem. Given Medicare's current commitments and future promises, the cost of this new proposal must be considered within the context of Medicare's existing fiscal responsibilities and costs. For example, the Part A Trust Fund remains financially unstable, Part B premiums have risen dramatically in recent years, and the new catastrophic legislation will increase premiums and income taxes substantially.

Summary

In summary, HIAA believes that this hearing will serve as a strong catalyst for further discussion on solving the nation's long term care financing crisis.

In designing the structure of a future public and private sector financing arrangement, HIAA believes that more analysis needs to be done to determine the most effective model for a shared responsibility and to determine the most fiscally responsible system over the long run. We need to explore more ways to achieve this balance before settling prematurely on any untested concept.

HIAA believes that the flexibility of private insurance initiatives offers the preferred approach to prefunding long term care for the majority of Americans. Private initiatives also provide maximum choices and flexibility to informal caregivers. And, over time, we believe private insurance will help reduce public spending for this care.

Thank you, Mr. Chairman, for the opportunity to appear today. I look forward to an on-going dialogue with you and your staff as the we move forward.

The **Chairman**. If the panel could remain for a few moments, I want to get into the record some of the technical questions, so I will ask my counsel to take the Chair, if he would.

Again, I apologize to you. I know you have some sense of what we have been up against here. Generally, we don't have the votes in the morning, and we would have been able to get through it. But I thank you all very much, and we look forward to working with you. We are going to be faced with this issue for some time, and we are going to need a lot of expertise. We know we don't have uniformity of opinion on this issue now, but hopefully, we can build a coalition to deal with it.

Counsel.

[Whereupon, Mr. David H. Nexon assumed the Chair.]

Mr. **Nexon**. Before I put some questions to the witnesses, Professor Weissert, maybe you'd like to finish your remarks. I know you were cut off before you had quite concluded.

Dr. **Weissert**. I was pretty close. The main point I wanted to make was that I think the notion of separating the coverage of nursing home care into two populations—people who stay less than 6 months and those who stay more than 6 months—is an extremely sensible thing to do. People who stay less than 6 months have a very good chance of going home. Having their financial liquidity kept intact might help that happen. After 6 months, you are really looking at estate protection. People who in all likelihood are going to die in the hospital or nursing home, suggesting that having coverage for them means that you allow them to make a bequest. While that is a perfectly reasonable thing to do, it is also probably reasonable to ask that the potential estate pay some of the premiums, which is what your bill does. It makes it optional. I think that is an excellent distinction.

Mr. **Nexon**. Thank you very much.

Mr. Lanzikos, there are a couple of questions I'd like to pose. One of the points you made in your testimony was that a majority of other States have programs in this area, although Massachusetts is clearly one of the better ones, and the capacity is there to build on it if we were to implement a national program of the kind proposed in this bill.

Is that a fair statement?

Mr. **Lanzikos**. I think that is a very accurate statement, Mr. Nexon.

Mr. **Nexon**. So there is no question that particularly if we provide resources for training and for technical assistance that the home care sections of the Lifecare Program could be implemented nationwide in a reasonable period of time?

Mr. **Lanzikos**. I think the key aspect in your question and statement is with the additional technical assistance and training that you do envision in the bill. I think one of the laudable characteristics of the proposal is that you do have a lead-in time. We do have the raw material that is available. We do have the systems and subsystems. But what we do need to do is have that opportunity to meld it into the more sophisticated system that you envision.

Mr. **Nexon**. Even in a State like Massachusetts, which clearly has a very excellent program, the fact is that the program, because of the resources of the State, is only able to reach a fraction of those who need help. Is that a fair assessment?

Mr. LANZIKOS. In Massachusetts presently, we have a little over 1 million people who are over the age of 60, and approximately 5 percent of them are in nursing homes, and almost 5 percent are in our community care system. So we are right now caring for about 10 percent of that population.

But I would have to say to you today that with additional resources, both additional financial resources that would be available to the program, as well as a different structural capacity, that we can in fact even be doing a better job; we could be doing more as well as we could be doing services at an earlier stage that would actually maintain people in less restrictive and more desirable environments.

Mr. NEXON. Thank you very much.

Professor Weissert, I want to thank you for your insightful testimony. I'd like to underline some of the points you made, because I know you have very rich and varied research experience in this area.

First, with regard to home care, what is the evidence of the studies you have examined on the difference that the availability of home care services can make in people's lives?

Dr. WEISSERT. Well, the major difference is in increased life satisfaction. Patients who get it experience a higher life satisfaction and family caregivers experience higher life satisfaction. There has been some disappointment that we don't see larger effects on mortality and morbidity, but I think that was kind of a poorly based expectation. This is not a clinical intervention. Home care is mainly supportive, and what you should see is increased life satisfaction. That's what you get.

Mr. NEXON. So essentially what you have is a situation where both the disabled elderly person and the people who care for them are better off and feel happier about their lives and are relieved at some of the crushing burdens that they would otherwise experience.

Dr. WEISSERT. That is correct.

Mr. NEXON. Some people have expressed concern that providing a public program of the kind envisioned in Lifecare will displace or reduce the voluntary efforts that people make to care for a parent or a spouse at home.

Would you comment on that concern?

Dr. WEISSERT. Yes; again, we have had research that directly address that issue in several studies, and they are in very close concert in showing that the support offered by family members drops only very slightly. The main effect is to redirect some of the efforts of family members away from skilled tasks—things like therapies, which they feel uncomfortable doing. They turned those over to the better-trained, skilled person. But they don't give up the tasks that many of us would think would be the most burdensome and difficult and distasteful. They continue to do those.

Mr. NEXON. So people continue to care for their relatives, but the task of caring for them is made easier by the availability of additional resources.

Dr. **Weissert**. Yes; the whole fear that this would drive out family provided care has proved unfounded.

Mr. **Nexon**. You have examined the list of services that may be provided under the home care benefit. Would you comment on that list? Are there some services that should be provided that are not included? Are there any that should be included that are omitted? What is your professional judgment of that segment of the bill now?

Dr. **Weissert**. Well, I noted that it was a more comprehensive list than some of the other bills have had. I thought it was an excellent list. It covers everything that we have studied to this point, which is really quite extensive. If I were going to raise a question about anything in the list—I am doing a national survey of adult day care programs, and I noticed that one of the requirements for adult day care in the legislation is that it have a full-time registered nurse. And I would question whether that is required in every case. That would be the single exception that I would see.

Mr. **Nexon**. Thank you.

I have just a few additional questions. You had very favorable things to say in both your written and oral testimony about the structure of the nursing home benefit, the full coverage for the 6 months, and then the voluntary partially premium-supported enrollment for the longer periods. There are obviously alternatives to that approach which could also reduce the public cost somewhat of covering nursing home stays. One alternative would be to provide for full coverage throughout a stay from public dollars, but to provide for high copayments throughout a stay. Would you comment on that alternative? What are the advantages and disadvantages of this approach as opposed to the one taken in the bill?

Dr. **Weissert**. Well, if it was going to be a long stay, the high copayment would still wipe out the person financially, so you really have not achieved your objective of financial protection.

And the other major drawback is that it would continue to aggravate the access problem. Nursing homes, because they are businesses, would continue to prefer patients who could make the copayment, and you'd have unequal access. And that is one of the things that a universal benefit does away with, is problems of unequal access due to income.

Mr. **Nexon**. OK. Another alternative is to have a long initial deductible, perhaps as much as a year or two years in some proposals. What do you think about that approach?

Dr. **Weissert**. Well, the biggest problem is that the poor couldn't afford to pay it, and so they would again be treated differently and have two-tiered care.

The other problem is that most of the people who need a nursing home would not benefit from a huge deductible, because most stays are short.

The other problem is that it fails to take recognition of the fact that there are really two different populations using nursing homes—short stayers and long stayers—with very different needs. And the legislation that the Senator has proposed makes this distinction and makes good policy out of it. A huge deductible fails to do that.

Mr. **Nexon**. OK. We'll turn to Mr. Lifson in a moment to further explore this last question. But what is your view about private long-term care insurance as an alternative to a universal public entitlement of the kind proposed in this bill?

Dr. **Weissert**. Well, as an alternative to nothing at all, I think it has been a tremendous addition to the choice of options. But as an alternative to the universal benefit, I think you have to first look at the fact that as it is presently offered, it has an enormous number of exclusions, deductions, preconditions, and levels of care requirements that mean that most patients who need a nursing wouldn't qualify. For example, you have to come in at the skilled level, and most patients come in at the intermediate care level.

There is only one policy on the market now that has inflation protection. So I think because the information is lacking for sound actuarial estimates for private policies—right now, the companies have had to write such restrictive policies—that it will be very difficult for people to actually get coverage under the policies that are available now.

If those policies are improved over time, and many of these things are eliminated or relaxed, it will improve policies. But we will still be left with the stark reality that the people who buy it will be those who can afford it, and the people who don't buy it will be those who are most likely to need it. Even people who can afford it regard it as a very expensive proposition as it is currently structured. I met recently with a fellow who is a State representative from the AARP who had just looked over their own policy and decided to turn it down, because it was just too much money for him at his policy age. So I think the answer here is a universal benefit that does not have to have these kinds of exclusions, offers comprehensive coverage, and because you've got the 6-month Part A benefit in it, will keep premiums down to an affordable level under Part B.

Mr. **Nexon**. Thank you very much.

Mr. Lifson, you have talked in your testimony about some of the advantages of a private sector approach to this problem, and you have mentioned that there seems to be quite a lot of interest among the private companies in offering a broader, more comprehensive range of policies than they do today.

The current portion that private insurance pays for nursing home care is quite low, isn't it? It's about 1 percent—is that an accurate figure?

Mr. **Lifson**. About the same amount that Medicare pays.

Mr. **Nexon**. Which is about 1 percent, between 1 and 2 percent.

Mr. **Lifson**. Yes.

Mr. **Nexon**. Based on the kind of growth that you are seeing, how long do you think it will be before this rises to more meaningful figures? I mean, how long would you guess, or do you have a basis for making an estimate as to how long it will be before we might be covering, say, 30 percent of nursing home costs from private long-term care insurance?

Mr. **Lifson**. Well, you have to recognize that over half of nursing home expenses are already covered by private sources.

Mr. **Nexon**. I misspoke. By private insurance coverage.

Mr. LIFSON. By private insurance coverage. I don't have a definite estimate for you. I think there has been absolutely phenomenal growth over the last three years. I would expect that growth to continue and to expand. I would think over a reasonable period of time—say, the next 5 to 10 years—there would be a significant proportion of the population covered by long-term care insurance. With clarification of the tax status of such products that growth will expand even more. If employers were able to offer these products with some surity as to there tax favored status, even on an employee-pay-all basis, there would be significant growth.

I think employee plans will provide the greatest growth, as we have seen with regular health insurance.

Mr. NEXON. Through private employment-based coverage?

Mr. LIFSON. Through employment-based coverage, even on an employee-pay-all basis, yes.

Mr. NEXON. I wouldn't think, though, that private employment-based coverage——

Mr. LIFSON. Excuse me. We really have to separate out the populations that we are talking about. I think it is unreasonable to expect an individual who is already elderly, who has had no opportunity during their lifetime to provide for themselves, to expect them to do so. I don't think the insurance industry expects them to do so, either.

I think there are others who do have the opportunity to provide for themselves over their working lifetime, and we might as a society decide that that is a reasonable expectation.

Mr. NEXON. So you would say that the HIAA—you are today representing the HIAA—would say that there is a lot of potential for private employment-based group coverage for long-term care, but very little for coverage for the currently retired population; is that fair?

Mr. LIFSON. I think there would be a mix of that. I think the experience to date has been primarily in the older age categories. As you know, the first policies were restricted. With each month the policies offered are more comprehensive. Most of the policies I refer to in my testimony are currently bought by the older age population.

That will continue to grow. I think the biggest growth will be in the employment age population.

Mr. NEXON. Let me ask you a question—and I am sure you don't have the answer today, but perhaps you do, but I would like you to supply it for the record, if you would. You recommend a set of tax changes in your testimony. Have you or could you do some estimates about what the tax expenditure costs of those changes would be over time as the proportion of the population potentially taking advantage of that would grow?

Mr. LIFSON. As you know, there have been several pieces of legislation introduced that would accomplish these tax changes needed. The Joint Tax Committee and the Congressional Budget Office have been asked to cost them out. To date, as far as I know, they have not provided those estimates. We have looked to them to do those estimates because they are the arbiter of those numbers.

Mr. NEXON. Let me return to the question of the current elderly population. The Brookings Institution has recently released an exhaustive report on the potential of private long-term care insurance to meet the needs of our senior citizens for coverage. Have you examined that study?

Mr. **Lifson**. I am familiar with it.

Mr. **Nexon**. Let me read you its conclusion.

> Private sector approaches are unlikely to be affordable by a majority of the elderly to finance more than a modest proportion of total nursing home and home care expenditures or to have more than a small effect on the number of people who spend down to Medicaid eligibility.

Do you agree with that conclusion?

Mr. **Lifson**. I do not.

Mr. **Nexon**. Could you explain why not?

Mr. **Lifson**. I think there are several reasons for it. One is the actual modeling that they did. They have used a simulation model which is built upon a variety of assumptions. They have carried those assumptions through the simulation model out 30 years.

Simulation modeling is very good the closer you are to the event that you are trying to simulate. The technique is very dependent and highly levered with regard to the assumptions one makes. The further into the future one goes, the greater the impact of these small changes in assumptions.

I believe that some of the critical assumptions that they have made on savings rates and affordability questions could change their results dramatically. They didn't look at assets, they only looked at income for example. In fact, in their report, they allude to some other conclusions. I believe they are engaging in a new simulation using more current assumptions.

One other consideration is the policy that they modelled is already out-of-date. The attractiveness of the newer policies, I think, would also produce different results.

Mr. **Nexon**. I think that is an important point, because that study is going to be widely cited, as I am sure it already has been and I am sure you are aware. I would be interested if you would be willing to submit a detailed critique to the record so that we could share it with the authors and get their response to that.

Mr. **Lifson**. I would be more than happy to do that.

Mr. **Nexon**. Thank you.

Just to pursue it a little further—you have all been very patient—if we look at a private market—a private individual market as opposed to a private group-based market—my impression is that the economics are not very favorable compared to Government-based insurance. The GAO, as you know, has studied Medigap insurance policies and found that the retention rates, which are the amount of premium not paid out in benefits, ran between 10 and 40 percent, and some were even higher, in fact.

Is there any reason to suppose that the cost of marketing and administering long-term care insurance would be lower than Medigap insurance—and we are talking about a private market as opposed to a group-based market.

Mr. **Lifson**. I think there are several reasons to believe that it would be. I think it is a little bit of apples and oranges to compare the base of Medicare, which is now about $80 billion a year, to Medigap insurance. For example when you write a check, the cost of writing the check, is the same whether the check is for a large amount, such as to a hospital, or a small amount, such as for a copayment. The former is small as a percentage and the other is large. With regard to private long-term care insurance, I think there are several things one should keep in mind.

One is that long term care insurance is more like disability insurance than health insurance. For example, frequency of claims are less under disability insurance. Once an individual enters a nursing home, particularly if it is a long stay, they are going to be there presumably for the rest of their lives. Their stay is really one claim. A company may pay on a monthly basis, but the determination of amount to pay is made only once. Such simplified claims administration significantly reduces the expense of the plan.

There are sales expenses. There are taxes that insurance companies have to pay. The Government doesn't pay taxes. There are a lot of differences in the way accounts are kept. One has to be careful when making the comparison between government and private sector experience.

Mr. NEXON. What would you estimate that a reasonable estimate of retention rate would be for private long-term care insurance——

Mr. LIFSON. I am not sure that retention rates per se are an appropriate measure of efficiency with regard to long-term care insurance. With long-term care insurance, a policy is bought 20 or 30 years prior to when the event is likely to happen. You have to look at the life of that policy, in order to determine the relative efficiency of it. We don't have sufficient experience as yet to make those judgments.

So I'm not sure what a good answer would be on long-term care insurance.

[Additional material supplied for the record follows:]

STATEMENT OF THE AMERICAN ASSOCIATION OF RETIRED PERSONS

to the

COMMITTEE ON LABOR AND HUMAN RESOURCES

U.S. SENATE

on

LONG-TERM CARE

August 3, 1988

The American Association of Retired Persons commends the Chairman for his strong leadership on the issue of long-term care. AARP is pleased that the Chairman's legislation would begin to move the nation's long-term care system from a welfare to an insurance-based system. We appreciate the opportunity to comment on S. 2681, The Lifecare Long-Term Care Protection Act.

This statement for the record will show why AARP believes there is a need for a new long-term care system based on the principle of social insurance. It will also discuss the broad outlines of the type of system AARP favors. Finally, the statement will comment on the provisions of S. 2681.

THE NEED FOR A NEW LONG-TERM CARE SYSTEM

Long-term care is potentially needed by persons of all ages, not just older persons. Seven million American households today have a child or adult member who is chronically ill or disabled. Millions of chronically ill children and adults who need long-term care are outside of the current Medicare/OASDI system and are not covered under private insurance. Also, as medical technology has advanced, many people who need long-term care are now living longer than they would have in the past. For instance, children with lung disease, who 15 years ago would have died, now are able to live with the assistance of mechanical respirators. They can be dependent on respirators for years. These children represent only one population needing long-term care.

As people age they frequently fall victim to chronic illnesses such as Alzheimer's disease and osteoporosis. These illnesses lead to a long, slow decline in mental and/or physical functioning. People with chronic illnesses may need acute care for major bouts with other conditions such as heart attacks but their dominant need is for long-term care. A person with

Alzheimer's disease needs someone to monitor his behavior and to help with such basics as bathing and dressing. Osteoporosis can put a woman in a hospital because of a broken hip; but after the hospitalization, she will need help moving around the house and with preparation of meals until her bones mend.

Disability rates increase markedly with age. For example, only 7% of persons aged 65-74 need help with one or more "instrumental" or "basic" activities of daily living, compared with almost 45% of people aged 85 or older. And, this very old age group is the fastest growing segment of our population.

The need for a new system of long-term care extends beyond those who need the care to those--family and friends--who provide personal care and financial support. Family members are the cornerstone of the long-term care delivery system for the elderly. These caregivers typically provide care every day. According to the 1982 National Long-Term Care Survey, almost 3 out of 4 functionally impaired older Americans rely exclusively on unpaid care provided by families and friends. Another 21% rely on a combination of support from families and paid providers. Only 5% of the elderly rely solely on paid providers.

The need for long-term care leads almost inevitably to an unmanageable financial burden because the cost of care is often enormous. The cost of a year in a nursing home averages $25,000. Nursing home stays account for over 80% of the expenses incurred by older people who experience very high out-of-pocket costs for health care. Since few people can afford the expense of an extended nursing home stay, many end up on Medicaid after a financial catastrophe has occurred. While Medicaid picks up a substantial share, more than half of nursing home costs are paid out of the pockets of residents and their families. The family's share of this burden has been rising in recent years.

Perhaps most important of all are the hidden costs of suffering, deprivation, and isolation for those in our society who get no care or inadequate help. Data from the National Long-Term Care Survey indicate that large numbers of functionally impaired older persons in the community, particularly the severely disabled, have unmet needs for assistance. For example, 77% of older people with three or more limitations in their activities of daily living reported they needed more help.

These factors--the need for long-term care among persons of all ages, the burden on families, impoverishment, and lack of care--demonstrate the need for a new approach to financing and delivering long-term care. AARP recommends a social insurance approach that protects all Americans from impoverishment and lack of care. Social insurance would require financial contributions from all members of society and would provide protection to all who need long-term care. The next section of this statement discusses the Association's recommendations for a long-term care program based on social insurance.

AARP'S RECOMMENDATIONS FOR A NEW LONG-TERM CARE SYSTEM

The country's primary governmental long-term care program, Medicaid, is inadequate for several reasons: 1) the Medicaid program does not cover home care except through special waivers; 2) among the services which Medicaid can provide, the degree of coverage varies dramatically from state to state; and 3) because it is a welfare program, Medicaid often robs families of dignity and independence. Beyond Medicaid, our society is paying the costs of long-term care but in a way that places burdens on the victims of chronic illness and their families. The question is how to spread the burden so that the costs to any one person will be small, while offering protection and appropriate care to all. The answer is a social insurance, rather than a welfare, approach.

The nature of the need for long-term care lends itself to an insurance approach based on shared risk for several reasons: 1) relatively few persons need long-term care at any one time; 2) it is nearly impossible to predict who these individuals will be; and 3) the lifetime risk of needing nursing home care is much higher than most people think. (The lifetime risk of institutionalization at age 65 ranges from 36% to 63%.) This combination of factors shows the need for and the utility of an insurance approach to universal protection. The costs to any one person will be small, while offering protection to all against financial devastation.

Americans of all ages recognize that long-term care is a growing necessity. While many underestimate the costs and the likelihood of their needing such service, surveys have demonstrated that the public is willing to participate in a social insurance approach.

AARP's recommendations for long-term health care encompass a number of issues and concerns. All Americans, regardless of age should be eligible for long-term care programs. The services offered by a nationwide, long-term care program should be inclusive. Nursing home care, day care, and in-home care all constitute particular and valuable resources to severely-disabled Americans who require assistance.

Some state governments already have experience in administering long-term care programs, and the Federal government would be well-served by a study of their experiences. These states have introduced a variety of programs and have demonstrated how flexibility and creativity in providing care can keep costs down while maintaining quality.

The federal government, however, must oversee development of long-term care programs to ensure that all Americans have access to quality services. Oversight must include strong standards relating to eligibility, services, administration, quality of care and provider reimbursement.

Eligibility for the New Program

Americans of all ages should have access to a new long-term care program. Chronically ill children and adults, as well as permanently disabled people, need access to long-term care. The lack of coverage of home and community services poses enormous burdens for these individuals and the families and friends who support them.

Eligibility for benefits should be based both on cognitive and functional impairments. Many people, particularly those who have Alzheimer's disease, may be physically capable of performing activities of daily living but unable to do so because of cognitive impairments. In determining eligibility for the program, in-person assessments and interviews with caregivers will be critical to gathering accurate information about individuals' functional status, social supports, and requirements for service arrangements.

The issues surrounding measurement of impairments are complex. For instance, there are several different scales for measuring the need for help with activities of daily living. In addition, it is not clear how to measure the need for help among different age groups. Thus, AARP recommends that a commission be established to assist the Secretary of Health and Human Services in developing appropriate measurements of disability, including a national, uniform assessment scale. The commission could provide advice on issues such as measurement of cognitive disabilities and the training needed by people who perform assessments.

Services under the New Program

AARP advocates that the program offer a wide range of long-term care services in the least restrictive setting possible. Services should include 1) in-home assistance, such as homemaker/chore services, personal care, home nursing care, and home-delivered meals; 2) community-based services, such as adult day care and transportation; 3) provision of home care services in special housing, such as congregate living arrangements; and 4) high quality institutional care. Another aspect of long-term care that merits consideration is respite care, which would provide short-term relief to unpaid caregivers, most of whom are family members. Such a broad range of services would ensure that people receive care that is tailored to their needs and circumstances. This would ensure the most efficient use of resources.

Administration of the New Program

The Federal government should take a strong role in administering the long-term care program to ensure that consistent standards for eligibility, quality of care, and reimbursement are maintained nationwide. Service delivery systems and the profiles of populations needing long-term care vary widely between and within the states. Thus, states will need to have some flexibility to tailor programs to meet their residents' distinctive needs. In addition, states should have a role in administration because a number of states have set up good service delivery systems.

Given that some states have more developed long-term care delivery systems than others, there is a need to phase in the new program. During the phase-in period, states should have technical assistance and start-up grants to enable them to develop their systems. The grants should be used to identify and fill gaps in service delivery networks. Since long-term care is currently biased toward institutional care, the initial emphasis should be on home and community-based services.

While the federal government has a very strong oversight responsibility and the states have a role in administering the new long-term care program, case management agencies have the potential to make the program work at the local level. Case managers could have responsibility for determining program eligibility and beneficiaries' need for care, developing the appropriate plan of care; arranging for delivery of services; and helping to ensure quality of care. States with the most comprehensive long-term care programs have found that giving independent case management agencies responsibility for assessing peoples' care needs and for developing care plans promotes program efficiency. Thus, case management seems to hold promise both for helping people to secure appropriate services and controlling use of services. Appropriate use of services is the key to keeping utilization and program costs under control. More research is needed to determine the best case management models and the appropriate role of these agencies.

Provider Reimbursement

Provider reimbursement systems for long-term care services should be designed to ensure the delivery of quality care. Payment should also ensure that cost increases are controllable. Reimbursement should be accepted as payment in full so that providers do not try to overcharge residents or clients. States, through their nursing home reimbursement systems, have begun to deal with these issues, and their experiences should be examined for applicability to a federal system.

For example, a number of states have developed "casemix" reimbursement systems that are designed to encourage nursing homes to accept heavy-care patients and deliver the appropriate amounts of care. New York's resource utilization group system (RUGS) pays nursing homes according to the amount of resources necessary to care for residents. The heavier the residents' care needs, the higher the level of reimbursement. Such reimbursement systems can improve access to nursing home care for the most vulnerable residents. Other states, such as Oregon, are beginning to develop nursing home reimbursement systems that would relate payment levels to resident outcomes. The idea is to go beyond casemix reimbursement and reward nursing homes that, in accordance with the plan of care, deliver care that improves or maintains residents' functioning. Providers would not be penalized when residents' functioning declines as a result of a debilitating disease.

To contain cost increases under Medicaid, almost all states use some form of prospective payment for nursing homes. This type of reimbursement system encourages facilities to contain costs because they are not reimbursed for charges that exceed the payment rate. For example, if a facility spends more than the prospective rate allows on administrative overhead, it will not be paid for the excess charges. Under any program, it is essential to use a payment system that keeps cost increases at reasonable levels. However, payment rates should not be so low as to undermine delivery of quality care.

With regard to payment for home care, there is less of a track record at the state level. Thus, there is a need for research to determine the best methods of paying for home care. The research should focus on prospective payment that rewards delivery of quality care. Such a payment system should also be flexible in order to account for the varying needs of home care clients. For instance, some people may need short periods of intensive skilled nursing care, and others may need long-term help with activities of daily living.

Quality Assurance

Under a new long-term care program, the federal and state governments would be taking a much more direct role in the financing of care. There should be a concomitant increase in the Federal government's responsibility for ensuring the quality of care that providers deliver. To ensure nursing home and home care quality, the new program should build upon the landmark Nursing Home Reform legislation the Congress passed in 1987 as part of the Omnibus Budget Reconciliation Act.

Additional quality standards for provider participation in the long-term care program should address the following goals: 1) plans of care and actual services delivered must meet client and caregivers' needs; 2) providers should not be allowed to discriminate in admissions or service delivery on the basis of payment source; and 3) social isolation of clients should be prevented. In addition, case managers should be involved in the quality assurance process by eliciting clients' views of the quality of care.

State ombudsperson programs also should be expanded to have responsibility for investigating and resolving complaints about all types of long-term care providers. Local consumer councils should be involved in such quality assurance efforts.

Financing the New Long-Term Care Program

Identifying realistic and adequate funding sources for a comprehensive long-term care program is one of the toughest issues which the Congress and advocates of long-term care must address. AARP advocates a social insurance approach to funding. Our attention is focused on beneficiary copayments, deductibles, and premiums; payroll, estate, and gift taxes; and maintenance of government spending on current long-term care programs such as Medicaid. In evaluating various possibilities, we are guided by several general assumptions.

1. The burden of paying for long-term care should be shared between the retired and working-age populations.

2. Any new federal commitment to long-term care should not add to the federal deficit.

3. Mechanisms must be established to keep cost and use of services under control.

4. The system must not create perverse incentives for delivery of care in a particular setting. For instance, copayments for home care should not be excessive compared to those for nursing home care.

COMMENTS ON THE LIFECARE LONG-TERM CARE PROTECTION ACT

The Association views any piece of long term care legislation in light of the broad outlines presented above. Thus, the comments on S. 2681 are based on our preference for a comprehensive approach to long-term care. The remainder of this statement comments on eligibility, benefits, administration, provider reimbursement, and financing provisions for long-term care as proposed in S. 2681.

Eligibility

S. 2681 provides home and community-based services, including respite care, to persons 65 and over, to those under 65 who are eligible for Medicare because of disability, and to children 19 and under. The bill also provides nursing home coverage for individuals 65 and over for a period of 6 months--or up to one year if there is a reasonable chance the person will return home. In addition, after an initial open enrollment period for all persons over age 45, the bill offers an option to purchase nursing home insurance coverage to persons at age 45 or at age 65 and above. Although the program would provide coverage to much of the population which needs long-term care, AARP is concerned that protection is not universal. Many disabled adults who do not meet SSDI requirements would be ineligible for services. Similarly, anyone under age 65 would be ineligible for full social insurance protection against nursing home costs.

AARP is reluctant to advocate a long-term care proposal that does not offer comprehensive coverage to all people. Our children and grandchildren need long-term care--both community-based and institutional. How can we meet our own needs without endeavoring to meet theirs too?

Benefits

The Lifecare program would offer a wide range of home care services and 6 months of nursing home care, with coverage for up to one year if there is a reasonable possibility that the person will return home. A voluntary insurance plan would provide nursing home coverage for more than six months for those who buy into the plan. There are a few advantages to these benefits:

1. There would be a major expansion of home care benefits for people who could remain in the community.

2. People would have immediate access to care and those likely to return to the community after a bout in a facility would receive the asset protection necessary for them to return.

Unfortunately, there also are several drawbacks to this benefit structure.

1. People who could not afford the optional nursing home insurance coverage and who, after six months, are not judged likely to be able to return home, would have to spend down onto the Medicaid program to obtain payment for nursing home costs. Thus, the six months of nursing home coverage does not assure catastrophic protection against the ruinous costs of care. The six month limit also will continue the current two-tiered system of care for public and private paying residents. Any long-term care program should ensure

catastrophic protection.

2. Although it is assumed that individuals could purchase the optional federal insurance or private insurance to provide protection for long stays, there are several reasons why this may not be a viable option for many people, particularly for those at high risk of long stays.

   Women comprise the majority of the elderly population, particularly of the 85 and older age group. Since functional disability increases with age, women are more likely to need long-term care. Women are also more likely to be living alone than are men, a factor which increases the risk of institutionalization. Both of these factors contribute to a dramatic difference in length of nursing home stay by gender - women having much longer stays than men.

   Since women are both more likely to need nursing home care and to have longer stays once institutionalized, they have the greatest need to purchase the insurance for nursing home stays exceeding 6 months. However, many elderly women may not be able to afford coverage. While women constitute approximately 60 percent of the elderly, they account for close to 75 percent of the elderly poor. Older women have poverty rates that are two to three times as high as older men.

   We are concerned that the cost of insurance coverage for nursing home stays that exceed six months may place a disproportionate burden on unmarried older women, who are particularly at risk of needing nursing home care, but who typically have low incomes and will be the least able to afford the premiums. A long-term care insurance program should include a mechanism to ensure that individuals who cannot afford premiums will not be left unprotected.

3. Private insurers will be reluctant to insure "high risk" individuals, and will likely develop underwriting procedures to screen them out. Those with existing impairments will not be eligible for private coverage at all. This will lead people who are at high risk of needing care to purchase the optional public insurance program. This adverse selection would raise the costs of such a program.

4. A public program offering coverage for 6 months only, will also provide incentives to residents to move "in and out" of nursing homes. How would this be controlled under the program? This may not be an easy issue to resolve in light of the fact that many people legitimately move "in and out."

5. While current data show that the likelihood of returning home after six months is small, such data are not reliable indicators of how many persons will be able to do so in the future, particularly in light of the proposed expansion in home and community based care. In addition, the short-term nursing home coverage implies that a nursing home resident who is unlikely to return home has little need to retain his or her life savings. This sends a dispiriting message to older people concerning their likely fate.

Administration

Long Term Care Agencies would determine program eligibility and would design care plans. If a state declines to establish and administer an agency, the Secretary would contract with a non-profit organization. In addition, the agencies can subcontract with non-profit organizations to perform case management. The bill states that case managers may also be employed by a certified home health agency or a home care agency. If so, there could be conflict of interest concerns. Under such a system agencies could design care plans that would direct clients to the services that the agencies offer.

In addition, the bill does not address how to integrate the Lifecare program with Medicaid, the Older Americans Act and other programs that provide long-term care. Existing programs would have to be carefully integrated with Lifecare to promote efficiency and avoid confusion.

Provider Reimbursement

The reimbursement for nursing homes would be prospective if possible and payment for home care during the first three years of the program would be limited to 65% of the average monthly cost of care in a facility. We have two recommendations:

1. Nursing home payment definitely should be prospective to contain costs. It also should take into account resident case mix so that facilities accept people needing heavy care.

2. Home care payment should be flexible to accommodate clients' potentially sporadic need for care. A person just discharged from the hospital may have short-run, heavy care needs that cost more than 65% of the cost of nursing home care. This concern, which is not fully addressed in many long-term care proposals, reflects the need for additional exploration of issues related both to payment and to integration of a long-term care program with the current system.

Maintenance of State Effort

States would be required to contribute what they would have spent on long-term care in the absence of the Lifecare Program, updated annually based on program cost increases to the extent proposed in S. 2681. While we believe that states must continue to play a role in financing long-term care, it is also obvious that such a strict maintenance of effort requirement could diminish states' budgets for other health programs and place an unacceptable burden on other needy populations. We question the states' ability to finance these cost increases. Program costs could escalate sharply as the population ages and demand for long-term care services increases.

CONCLUSION

The Association commends you for the significant contribution which the Lifecare Long-Term Care Act makes to nationwide debate on the long-term care needs of America's elderly population, disabled adults, and children 19 and younger. We reiterate the Association's strong commitment to achieving the goals embodied in the program and we urge you to extend comprehensive protection under this Act to provide universal coverage so that no American lacks protection against the costs of long-term care.

Mr. Nexon. Thank you all very much.

[Whereupon, at 12:50 p.m., the committee was adjourned.]

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